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**An exploration of community neuropsychological
rehabilitation following acquired brain injury: psycho-
social outcomes and narratives of identity**

Rohan Cook

Doctorate in Clinical Psychology

September 2016

Submitted in part fulfilment of the degree of Doctorate in Clinical Psychology at the
University of Edinburgh.

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Overview of thesis

This thesis follows the portfolio format and the following information provides a brief summary of the main chapters of the thesis:

Chapter 1 is a systematic review of the research literature reporting the psycho-social outcomes of community-based holistic neuropsychological interventions. Chapter 2 is a narrative analysis of the experiences of 11 individuals following acquired brain injury, their personal identity and experiences of rehabilitation. The appendices to both chapters are then provided.

The systematic review and empirical journal article were written for submission to the journal *Neuropsychological Rehabilitation*. The author guidelines for this journal are included in appendix L.

Word count: 23, 275 (not including references and appendices).

Glossary of key terms

Holistic neuropsychological rehabilitation – An evidence based treatment approach developed to treat individuals post acquired brain injury. The ‘holistic’ element of this treatment refers to the comprehensive nature of the multimodal approach, including; interventions which target neurological, psychological and social functioning; outcome-orientated patient centred rehabilitation planning; and conducted within a *therapeutic milieu*.

Therapeutic Milieu - The organisation of the rehabilitation environment in order to maximise social support and participation whilst facilitating the process of adjustment. A limited definition of this might include providing interventions within a group setting, in which individuals may discuss rehabilitation strategies and provide feedback regarding personal experiences of rehabilitation to both clinicians and other participants. Deeper ‘milieu’ may include delivering interventions in *real world* situations or using roleplaying e.g. to practice communication strategies.

Treatment intensity (referred to as high or low) – Intensity refers to the *frequency* and *amount* of time an individual spends in rehabilitation over the course of a week. Definitions of high and low intensity have been based on existing clinical practice. High intensity interventions involve attending multiple full days of treatment per week. Low intensity interventions are therefore considered to be those which are delivered at a frequency of one day a week.

Thesis Abstract

Introduction: High intensity holistic neuropsychological rehabilitation is the most evidenced-based intervention for post-acute ABI rehabilitation. However, the majority of the current evidence has examined inpatient or residential treatment contexts. Little is known about the efficacy of community neuropsychological rehabilitation interventions or the clinical validity of both high and low intensity forms of rehabilitation in a community rehabilitation setting. The systematic review synthesises the existing evidence for community-based holistic neuropsychological rehabilitation and its psycho-social outcomes.

Changes in self and group identity have been suggested to underpin evidence-based neuropsychological rehabilitation. However, little is known about how these processes of identity change following ABI and throughout the rehabilitation process. The empirical study explores key turning points in the self-narratives of individuals with ABI in order to better understand the clinical and contextual factors which influence their rehabilitation.

Methods: A search was conducted of Embase, Embase classic, Medline and PsycInfo. Studies were assessed for risk of bias and outcomes were synthesised following the PRISMA guidelines for systematic reviews.

A 'holistic-content' narrative methodology was then employed to explore the post-acute adjustment and rehabilitation narratives of 11 individuals following ABI. Three-dimensional analysis of *interaction*, *continuity* and *situation* was used to examine individuals' personal reflections of identity changes across their illness experience; and cross-case comparisons identified common transformational themes.

Results: 15 studies were included in the review. Two distinct levels of intervention intensity were identified: high intensity interventions delivered multiple days per week, and low intensity interventions delivered only once a week. A synthesis of nine studies examining high intensity neuropsychological rehabilitation found evidence that these interventions can improve psychological wellbeing and enhance community integration following ABI when delivered on an outpatient basis. A synthesis of six low intensity interventions found limited evidence that they can lead to improved psycho-social outcomes when structure to target specific difficulties, and

evidence that they can effectively support the achievement of individual patient goals.

Following the analysis of ABI survivor narratives, themes of 'Rehabilitation focus and psychological distress', 'Reclaiming efficacy in valued life domains', and 'Social comparisons: inclusion and exclusion' were identified; each representing a continuum of personal and social understanding along which people moved during their rehabilitation.

Conclusions: The systematic review suggested that high intensity forms of outpatient neuropsychological rehabilitation are effective at improving psycho-social outcomes. Low intensity forms of outpatient neuropsychological rehabilitation appear to offer a less favourable alternative to supporting psycho-social adjustment in the community at present.

Findings from the empirical paper suggest that illness identity may be co-constructed in the context of early treatment experiences, and appears to influence post-acute rehabilitation focus; and that pre-injury values and self-identity guided participant approaches to re-establishing self-efficacy. These processes were supported by clinical, social and group interactions.

Chapter 1: Systematic review

A systematic review of the psycho-social outcomes of community-based holistic neuropsychological rehabilitation for patients adjusting to acquired brain injury

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Abstract

Introduction: High intensity holistic neuropsychological rehabilitation is the most evidenced-based intervention for post-acute ABI rehabilitation. However, the majority of the current evidence has examined inpatient or residential treatment contexts. Clinical and social priorities in health are increasingly shifting towards longer-term functional outcomes from chronic conditions such as ABI. Little is known about the efficacy of community neuropsychological rehabilitation interventions or the clinical validity of both high and low intensity forms of rehabilitation in a community rehabilitation setting. This review synthesises the existing literature in this area, with a specific focus on holistic forms of rehabilitation and their psycho-social outcomes.

Method: A search was conducted of Embase, Embase classic, Medline and PsycInfo. Studies were assessed for risk of bias and outcomes were synthesised following the PRISMA guidelines for systematic reviews.

Results: 15 studies were included in the review. Two distinct levels of intervention intensity were identified: high intensity interventions delivered multiple days per week, and low intensity interventions delivered only once a week. A synthesis of nine studies examining high intensity neuropsychological rehabilitation found evidence that these interventions can improve psychological wellbeing and enhance community integration following ABI when delivered on an outpatient basis. A synthesis of six low intensity interventions found limited evidence that they can lead to improved psycho-social outcomes when structured to target specific difficulties, and evidence that they can effectively support the achievement of individual patient goals.

Conclusions: This review suggests that high intensity forms of outpatient neuropsychological rehabilitation are effective at improving psycho-social outcomes. Low intensity forms of outpatient neuropsychological rehabilitation appear to offer a less favourable alternative to supporting psycho-social adjustment in the community at present.

Key words: Acquired Brain Injury; Neuropsychological Rehabilitation; Community; Low intensity; Systematic Review.

Introduction

Acquired brain injury (ABI) is defined as any damage to the brain which was of sudden onset and occurred after birth (Scottish Intercollegiate Guidelines Network [SIGN], 2013). This definition encompasses a wide range of disorders of varying aetiologies, which can affect virtually any aspect of a person's functioning (Ownsworth, 2014). The impact of ABI often extends beyond individual neurological changes and often leads to neuro-behavioural changes, emotional disorders and significant social disruption (Sohlberg & Mateer, 2001). The burden of caring for and supporting individuals in the community can also have a significant psychological impact on close family members (Oddy & Herbert, 2009).

Despite the heterogeneous nature of ABI, rehabilitation service provision often focuses on the common features of these conditions rather than specific pathological diagnoses (Turner-Stokes, Disler, Nair, & Wade, 2005). Traditionally, rehabilitation service delivery has been concentrated on physical rehabilitation and remediation for cognitive impairments (McMillan, 2005; Sohlberg & Mateer, 2001). A series of systematic reviews of post-acute rehabilitation identified the need for research to re-focus on long term functional and social outcomes most pertinent to the needs of patients and their families (Carney et al., 1999; Chesnut et al., 1999; Cicerone et al., 2005); and clinically there has been a push for services which can prepare patients for the psychological and social consequences of their injuries (Williams & Evans, 2003). This shift in the conceptualisation of outcomes in ABI reflects the World Health Organization's (WHO) International Classification of Functioning (ICF), which aims to shift national government's health policy and planning from emphasising *disability* to incorporating broader 'bio-psycho-social' notions of *functionality* (World Health Organization, 2001). In light of this shift there is a need for rehabilitation service commissioners to consider which interventions may best meet ABI patients' long term holistic psycho-social needs, in addition to considering physical outcomes.

The strongest evidence for post-acute rehabilitation which benefits psycho-social outcomes is for 'holistic' forms of high intensity neuropsychological rehabilitation (Cattalani, Zettin, & Zoccolotti, 2010; Cicerone et al., 2011). These interventions were pioneered in an inpatient setting, where the clinical environment can be carefully controlled to maximise the benefits

of a therapeutic milieu¹ alongside intensive co-ordinated multidisciplinary rehabilitation incorporating cognitive rehabilitation, group psycho-social adjustment and family support (Prigatano, 1999; Sarajuuri & Koskinen, 2006). High intensity specialist neurorehabilitation for moderate to severe ABI have been estimated to reduce the cost of supporting individuals in the community by up to 1 million pounds² per annum (Wood, McCrea, Wood, Merriman, & Wood, 1999; Worthington, Matthews, Melia, & Oddy, 2006); however these interventions require significant resources to establish and maintain, and patients often have to be admitted to specialist residential units for treatment of periods in excess of six months. Turner-Stokes et al.'s (2005) Cochrane review of multidisciplinary rehabilitation for ABI emphasises the need to balance such interventions with the long-term cost-effectiveness of treatment. They suggest that services seek to optimise the most efficient levels of intensity and recommend lower intensity treatments for less severe brain injuries. Alongside short and long-term resource implications it is also pertinent to consider the availability of these specialist services to those ABI patients who may potentially benefit.

Many patients who suffer an ABI are not referred for specialist inpatient treatment, either because their injuries are not deemed severe enough or because the functional consequences of their injury are not appropriately assessed prior to discharge (Jackson & Hague, 2013). A cohort study in the Scottish health context found that 47% of ABI survivors with a moderate to severe functional disability reported that they had not been seen in hospital in the year following discharge, and only 28% reported receiving any input from rehabilitation service (Thornhill et al., 2000). This is particularly concerning given that ABI survivors may not present themselves for assistance without routine follow-up due to lack of awareness (Chard, 2006). There is strong evidence of the chronic psycho-social and psychiatric consequences of ABI for both survivors (Fleminger, 2008, 2010) and their families (Oddy & Herbert, 2009). In the longer term many ABI survivors are likely to require community based neurorehabilitation to support them with the cognitive and emotional problems associated with ABI, either following discharge from acute treatment or to support the transition from post-acute inpatient rehabilitation (McMillan, 2005; Turner, Fleming, Ownsworth, & Cornwell, 2008). Clearly there is compelling justification to consider

¹ Therapeutic Milieu refers to the organisation of the complete environment in which rehabilitation occurs in order to maximise social support and participation and facilitate the process of adjustment. For further information, see (Wilson, Gracey, Evans, & Bateman, 2009).

² For patients treated within the first 2 years of injury.

interventions which can meet the long-term needs of patients who are likely to present to community services with psycho-social difficulties during the challenging adjustment post hospital discharge, and in the longer term.

In light of an increased awareness of the long-term psycho-social needs following ABI, the UK government has developed a National Service Framework (NSF) for long-term conditions which places an emphasis on continuing access to rehabilitation in the community and the development of specialist service provision. Quality requirement 5 of the framework states:

“People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.”

(Department of Health [DoH], 2005)

In Scotland, it is acknowledged that post-acute inpatient rehabilitation is not currently available comprehensively through the country (SIGN, 2013) and community rehabilitation services have been tasked with providing both short and long term rehabilitation to patients with ABI (Scottish Acquired Brain Injury Network [SABIN], 2009). In line with the strongest research evidence, SIGN (2013) recommend holistic neuropsychological rehabilitation programmes are delivered in either an inpatient, or community setting. However; delivering comprehensive holistic neuropsychological rehabilitation presents a significant challenge for community rehabilitation services. This challenge is not unique to Scotland; rather, the UK and the USA are cited as leading the way in implementing community neuropsychological rehabilitation (Sarajuuri, 2006). Although local ABI teams are increasingly being developed, there is a paucity of expert resources and poor coverage in many areas (Jackson & Hague, 2013). Rehabilitation services looking to deliver resource intensive, evidence-based interventions in the community face multiple additional barriers; particularly in countries where populations are spread over large geographical areas (Ponsford, Harrington, Oliver & Roper, 2006). Delivering fully integrated ‘holistic’ milieu-based care in the community may be particularly challenging given that specialisms are often less integrated, and low staff to patient ratios mean that high intensity interventions may not be achievable (Coetzer, 2008; Glinthorg & Hansen, 2016). However, providing rehabilitation in the communities in which people live may benefit the generalisation of

rehabilitation strategies and cause less disruption to existing support networks (Jackson & Hague, 2013; Yates, 2003).

The UK Governments' NSF for long term conditions mandates that local authorities adapt services to meet 11 key quality requirements based on current evidence of best practice including: patient-centred services, early and specialist rehabilitation, community rehabilitation and support, vocational rehabilitation and supporting carers and families. This was to be delivered within a 10-year timescale utilising existing resource levels. In order to meet this need consideration must be given to how to adapt current services to provide effective evidence based care for this population identified as requiring long-term psycho-social support. As Jackson and Hague (2013) observe, this clearly represents a significant gap "between theory and practice at both a clinical and social policy level" (p152). The British Psychological Society (BPS) Division of Neuropsychology (2005) produced a report suggesting that existing local services could be integrated in order to create non-residential community brain injury rehabilitation centres. In response to this policy background one regional brain injury services produced a model for 'low intensity' holistic neurorehabilitation based on the evidence-based framework prominently delivered by specialist post-acute services and established multi-disciplinary working (Coetzer, 2008). Adapted 'holistic' group interventions have been trialled over the past decade, however these have only been considered within the context of wider reviews of the rehabilitation literature.

The majority of systematic reviews in this area have evaluated the evidence for brain injury rehabilitation generally rather than focussing on community rehabilitation or specific interventions. Early reviews which have included an evaluation of community rehabilitation for ABI have highlighted the lack of high quality evidence to support specific interventions and stopped short of making specific recommendations (Carney et al., 1999; Chard, 2006; Chesnut et al., 1999). Carney et al. (1999) highlighted the importance of a recovery focus over static clinical regimes, suggesting future studies attempt to consider clinical outcomes which impact psycho-social functioning, such as health and employment, rather than pursuing cognitive outcomes which may not have an applied benefit. In a later evaluation of the evidence base, Chard (2006) cites a lack of focus on "multiple dimensions of patient's psycho-social resources" (p532) as a key limitation of the current evidence base. In a Cochrane review of multi-disciplinary rehabilitation for ABI, Turner-Stokes et al. (2005)

found *limited evidence* that specialist multi-disciplinary community rehabilitation may lead to functional gains; and that a greater intensity of treatment is likely to lead to faster levels of recovery for those with most severe injuries. They recommended further investigation into the effectiveness of lower intensity approaches which target community based functional outcomes in line with the ICF. The importance of psycho-social focus over psychometric outcomes was echoed in a review by Rees (2007), who highlighted that few studies had examined executive functional (EF) deficits, despite EF often having the greatest impact on community functioning. In a comprehensive review of ABI rehabilitation Cullen et al. (2007) found *limited evidence* that community based social and behavioural rehabilitation of at least six months may result in higher social activity levels, greater independence and less reliance on care. When examining intensity of inpatient interventions, they highlighted the finding that 'more intensity is better' leading to greater functional and motor outcomes. A key gap was identified regarding community-based programmes, and little focus had been placed on clarifying the ideal timings, intensity and types of interventions which were delivered. More recently comprehensive/holistic neuropsychological rehabilitation has been recommended as providing the greatest overall improvement for psychosocial functioning (Cattalani et al., 2010; Cicerone et al., 2011). Cattalani et al. (2010) highlighted that only a third of studies which they reviewed reported treatment intensity, whilst only comprehensive-holistic and community based interventions appeared to focus on the generalisation of treatments to everyday functioning and naturalistic community environments. No systematic reviews have looked specifically at community holistic rehabilitation, rather, the above reviews have taken a general approach to the rehabilitation literature. However, the current consensus is that more focus needs to be placed on community rehabilitation and outcomes which relate to long term functional and psycho-social benefits for patients. Whilst the intensity of interventions is understood to be an important factor, none of the reviews to date have considered the evidence base for low-intensity community interventions specifically. Greater evaluation of the relative benefits of such interventions is called for; however, adapted low-intensity forms of community rehabilitation are relatively new (Coetzer, 2008) and the general 'scoping' approach taken in previous reviews has not led to a detailed systematic evaluation of these adapted interventions.

In summary, there is an increasing awareness of the long-term psycho-social needs of ABI survivors, even following evidence-based post-acute care. Within this context, there has

been a paradigm shift amongst policy makers, clinical researchers and ABI rehabilitation clinicians, looking to develop effective treatments to meet the most holistic needs identified by patients. Local authorities and community services have been mandated with a responsibility to deliver evidence-based treatments, however there is a lack of research identifying established interventions which are feasible to provide in a community rehabilitation context. There are gaps in the evidence relating to community based interventions which report psycho-social and related functional outcomes. In addition, treatment intensity has been identified as an influential factor, however little is known about the efficacy of low-intensity community rehabilitation. The aim of the current review is to evaluate the current evidence for both high and low intensity community holistic rehabilitation interventions, in order to better inform clinical practice and service delivery.

The current systematic review will examine the following question: What are the psycho-social outcomes of community-based holistic neuropsychological rehabilitation for adults adjusting to acquired brain injury?

Methods

The systematic review followed the PRISMA reporting protocol, which was developed to enhance research transparency (Moher, Liberati, Tetzlaff, & Altman, 2009). A hand sort of previous reviews was conducted to ensure reliability of the search criteria, and studies meeting the inclusion criteria were included.

Protocol and registration

A pre-registered protocol was not produced for this systematic review due to time limitations. The present study was designed, in collaboration with research supervisors, to provide a broad systematic scope of the published evidence for the psycho-social outcomes of community neuropsychological rehabilitation and no modifications were made to the outcomes of interest following the commencement of the study.

Eligibility Criteria

In keeping with the rationale outlined above, a review was conducted which sought to identify intervention studies which might best meet the needs of an adult outpatient ABI population in the *chronic* phase (over one year) post injury, seeking community-based support for adjustment to psycho-social difficulties. As shown in Table 1, studies were included if they were published between 2000 and August 2016 and reported psycho-social outcomes of a holistic neuropsychological rehabilitation intervention delivered in an outpatient setting for adults in the chronic phase post ABI. Previous systematic reviews have found that prior to 2000 there had been limited examination of the psycho-social outcomes of neuropsychological rehabilitation (Carney et al., 1999; Chesnut et al., 1999; Cicerone et al., 2005).

In order to capture both high and low intensity interventions, *holistic* neuropsychological rehabilitation was defined using the following minimal criteria: integrated cognitive and social rehabilitation, which was conducted at least partially in a group milieu and coordinated by qualified health professionals. These criteria were chosen to incorporate the main elements of holistic programmes outlined by Trexler (2000).

A broad and inclusive definition of ABI was used to reflect the clinical population treated by rehabilitation service providers, and in line with previous systematic reviews of the rehabilitation literature (Turner-Stokes et al., 2005). The chronic phase post ABI was considered to be anything over 1-year post injury, in keeping with a previous review of the rehabilitation literature (Geurtsen, van Heugten, Martina, & Geurts, 2010).

Outcomes were considered to be psycho-social if they contained subscales measuring psychological, executive functional or behavioural outcomes, community/social integration or quality of life measures. Studies were considered to be community-based if they were delivered on a non-residential outpatient basis.

Peer reviewed observational studies and randomised controlled trials (RCT's) were included, while case studies, conference abstracts, systematic reviews and descriptions were excluded from this review.

Table 1. Inclusion and Exclusion Criteria

Category	Criteria
Study population	Populations consistent of patients diagnosed with an acquired brain injury (ABI), minimally defined as damage to the brain sustained with sudden onset which occurred after birth. This is a heterogeneous category which includes traumatic brain injury (TBI), Stroke, tumour, hypoxia, and infections such as encephalitis; and excludes neurodegenerative diseases. Studies were excluded which did not specify that at least 90% of participants met at least one of these diagnoses. Injury severity was not an exclusion criterion. In order to be considered in the 'chronic' phase, mean duration post-injury was required to be over 1 year.
Study geography	Studies from all countries were accepted.
Factors / Interventions	All factors which pertained to psycho-social outcomes were included, this included validated measures which contained subscales relating to psychological wellbeing, social integration or participation, quality of life, functional impairments or behavioural difficulties; carer ratings of these factors were also included. Studies were included which reported pre and post analysis of non-residential holistic rehabilitation interventions.
Time period	Studies published between 1980 and August 2016 were included in the search. Only those published from 2000 were included in the review.
Publication language	Studies published in the English language only were included.
Admissible evidence	Case studies, conference abstracts, systematic reviews and case descriptions were excluded

Search strategy

A systematic review of the PsycINFO, Medline, Embase and Embase Classic databases was conducted from 1980 to August 2016. The following search terms were used:

Population terms: EITHER 'brain injury', 'acquired brain injury', 'traumatic brain injury', 'ABI', 'TBI' OR 'Stroke'. (Abstract, title or keyword fields)

AND

Intervention terms: EITHER 'neuropsychological rehabilitation', 'cognitive rehabilitation', 'neuro-rehabilitation', 'psychosocial rehabilitation', 'psycho-social rehabilitation' OR 'holistic rehabilitation'. (Abstract, title or keyword fields)

AND

Setting terms: EITHER 'community', 'outpatient' OR 'non-residential'. (Any fields)

In addition, previous reviews and included studies were hand search for additional studies which met the inclusion criteria. Duplicate studies were eliminated.

Study selection

Titles and abstracts identified by the above search were screened to remove studies which clearly did not meet the inclusion criteria (e.g. studies conducted in a non brain injury population or qualitative studies). The full text publications of remaining studies were then examined to determine eligibility using the inclusion/exclusion criteria.

Data collection process

A data extraction tool was developed and piloted on 5 randomly selected studies which met the search criteria (appendix A). Adjustments were made to the search tool to enhance extraction of the intervention intensity and design, as it became clear that there was a large amount of variability in the approaches taken. All full text articles were considered on a first reading using the extraction inclusion criteria checklist (appendix A - part A), data was then extracted from papers which were not excluded on first reading (appendix A - part B). Additional effect sizes were calculated using statistical methods where reporting enabled

this e.g. using t-scores, means and standard deviations. Authors were not contacted for additional data in this study.

Data items

Information was extracted from each study which pertained to the following: publication details; research design – cohort, observational or RCT, and details of control; sample source and selection; participant details – incl. demographics, diagnostic mix, mean duration since injury and co-morbidity (for both treatment and control where applicable); intervention description – multidisciplinary or specific-targeted, discrete or open ended, intervention components and guiding model (if reported), treatment intensity and contact hours; psycho-social outcomes, significant effects and effects sizes (where reported).

Table 1. ‘Study selection’ defines all variables for which data were sought and outlines assumptions and simplifications made. Further clarification of key definitions is given in the glossary (p6) and in the eligibility section above. Measures were reported if they pertained to constructs of psychological wellbeing, social integration or participation, quality of life, functional impairments, behavioural difficulties, activities of daily living or personal goals.

Quality assessment

Observational studies were rated for risk of bias using the Agency for Healthcare Research and Quality (AHRQ) assessment tool (J. W. Williams, Plassman, Burke, Holsinger, & Benjamin, 2010). This tool enables an assessment of the potential for bias introduced through study design and protocol. *Appropriateness* of sample selection and reporting, methodological and analytical approach and completeness of data, were all assessed as either “Yes”, “No”, “Partially” or “Can’t tell” (appendix B). Randomised control trial studies were rated using the Cochrane Risk of Bias tool (Higgins, Green, & Cochrane, 2008), which assesses for risk in of bias in study design, implementation and reporting. Studies were rated as either “low risk of bias”, “high risk of bias” or “unclear risk of bias” across six stated domains (appendix C). Eight of the studies which met the inclusion criteria were independently rated for bias by a second researcher, any inconsistencies in rating were resolved through discussion. Assessments of quality informed the results synthesis.

Summary measures

All significant psycho-social measures were extracted and reported in the study characteristics table 2. Effect sizes were extracted or calculated (where reporting allowed) and Cohen's *d* effect strengths were reported in the main text: small, medium or large. More detailed reporting of effect sizes and methods of extraction are given in appendix E.

Synthesis of results

Results were collated and analysed using a narrative synthesis as there was insufficient conceptual similarity between studies to attempt a meta-analysis.

Results

Study selection

The process of study selection is represented in the PRISMA diagram below (figure 1). Of the 608 papers identified following the removal of duplicates, 553 were excluded on examination of title or abstract. Full text publications were review for the remaining 55 papers, following which 30 papers were excluded; 12 did not meet minimum criteria to be considered holistic interventions, 6 did not contain both pre and post measures, 5 were reported inpatient or residential trials, 2 were case studies, a further 5 studies were excluded for individual reasons. A full list of the studies excluded with reasons is contained in appendix D.

A total of 15 studies were included for review. All of the included studies reported pre and post measure for holistic forms of neuropsychological interventions, as defined by the minimal criteria described above. Study characteristics are provided in Table 2.

Risk of Bias

AHRQ rating for observational cohort studies and non-randomised controlled trials are provided in Table 3. Cochrane Risk of Bias ratings are provided in Table 4.

Treatment intensity

As anticipated, two substantially different levels of intensity³ were clearly identifiable within included papers. 9 studies reported *high intensity* outpatient holistic neuropsychological rehabilitation approaches, delivering multiple days of rehabilitation per week; 6 studies reported *low intensity* outpatient neuropsychological rehabilitation approaches which were delivered less than one day per week over the course of the intervention. Corresponding to the differing levels of intensity there were further key differences in the overall structure of the interventions, with high intensity programmes offering more multidisciplinary and individual therapeutic sessions alongside neuropsychological group interventions. Level of intensity is understood to influence functional outcomes of neuropsychological rehabilitation (Cullen, Chundamala, Bayley, & Jutai, 2007; Turner-Stokes et al., 2005). In consideration of these differences, the two levels of intensity could not be considered conceptually similar enough to be grouped and have been synthesised separately.

³ Defined by the number of days of rehabilitation per week: high <2 days, Low 1 day only.

Figure 1. PRISMA flow chart of study selection

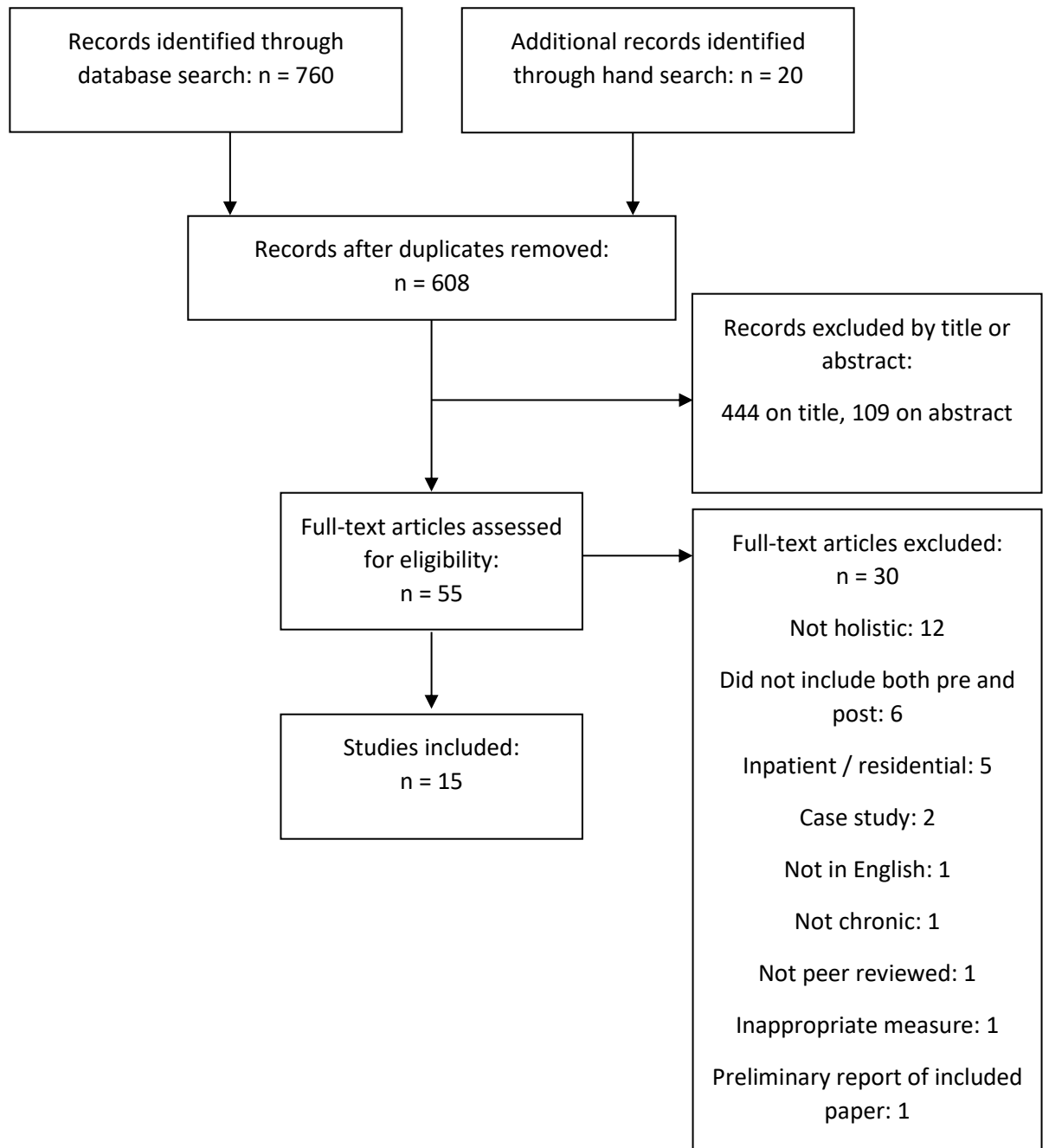


Table 2: Characteristic of included studies

Authors, year, country	Design	Sample source	Participants (N, characteristics / control)	Neuropsychological intervention, intensity and duration; Control and (follow up)	Psycho-social outcome measures used	Psycho-social outcomes: (Significant changes, Effect sizes)
Brands et al. (2013) The Netherlands	Cohort	Outpatient neuropsychological rehabilitation	N = 26*, 73% male, mean age: 44.6; Diagnosis: TBI 38%, stroke 35%, SAH 15%, other ABI 12%; severity unknown Mean time since injury: 3 yrs. *plus data from 23 carers	Individually tailored, MDT, 'adjustment-orientated' approach: Individual, group and carer sessions. <i>Low intensity:</i> mean input of 66.7 hours over 8.8 months; weekly carers group – 1hr 45mins (6 month follow up)	Stroke-adapted Sickness Impact Profile (SA-SIP30) Cognitive failures questionnaire (CFQ) Goal Attainment Scaling (GAS) Frenchay Activities Index (FAI) Community Integration Questionnaire (CIQ) *Carer strain index (CSI) *Utrecht Coping List (UCL)	Sig. (within groups): GAS – <i>Goal attainment</i> , effect size not known. Sig at discharge and follow up. Not sig.: QoL (SA-SIP30), CFQ, ADL (FAI), CIQ, CSI, UCL
Caracuel et al. (2012) Spain	Cohort	Trauma rehabilitation unit	N =18, 83% male, mean age 30.37; Diagnosis: TBI 56%, stroke 44 %; 100% severe Mean time since injury: 12 mnths	Holistic model: Group programme, with carer training. <i>High intensity:</i> 26 weeks, 9 hrs/w with patients, 3 hrs/w with carers (12 month follow up)	European Brain Injury Questionnaire (EBIQ) – self and carer rated Frontal Systems Behaviour Scale (FrSBe)	Sig. (within groups): EBIQ – <i>social and emotional regulation</i> (improved – self and carer rating), large effect at follow up. EBIQ – <i>depressive mood</i> (improved – carer rating), large effect at follow up. EBIQ – <i>cog. dys.</i> (improved – sig. Carer rating), large effect at follow up. FrSBe – <i>apathy</i> (improved self and carer rating), large effect at follow up. FrSBe – <i>Exe. dys.</i> (improved self and carer rating) large effect at follow up)

Authors, year, country	Design	Sample source	Participants (N, characteristics / control)	Neuropsychological intervention, intensity and duration; Control and (follow up)	Psycho-social outcome measures used	Psycho-social outcomes: (Significant changes, Effect sizes)
Sig. = Significant effects; Not sig. = No significant effect from measure; QoL = Quality of life; ADL = Activities of daily living; cog. dys. = Cognitive Dysfunction; Exe. dys. = Executive dysfunction						
Cicerone et al. (2004) USA	Non-randomised controlled trial	Post-acute outpatient brain injury rehabilitation program	N = 56 (27/29), 71% male, mean age 37.8/37.1; Diagnosis: TBI 100%, 88.9/89.6% mod-severe Mean time since injury: 33.9 mths/ 4.8mths	Intensive cognitive rehabilitation programme (ICRP): group and individual sessions and work trial. <i>High intensity:</i> 16 weeks, 15 hrs/w therapy, 1 day/w work trial. Control: Multidisciplinary, NR programme – individually delivered with work trial. (No follow up)	Community Integration Questionnaire (CIQ)	Sig. (within groups): CIQ – <i>Overall score</i> , large effect for treatment group, medium effect for control. <i>Significant difference by group</i> (intervention over control) for <i>home integration</i> and <i>productivity</i>
Cicerone et al. (2008) USA	RCT	Post-acute outpatient brain injury rehabilitation program	N = 68 (34/34), 62/74% male, mean age 34.5/38.7; Diagnosis: TBI 100%; Mild 18/9%, Mod 10/6%, Severe 17/23%; Mean time since injury: 37 mths / 49.6 mths	Intensive cognitive rehabilitation programme: group and individual sessions, meta-cognitive and group focus. <i>High intensity:</i> 16 weeks, 15hrs/w therapy Control: Multidisciplinary, NR programme - predominantly individual, limited group. (6 month follow up)	Community Integration Questionnaire (CIQ) Perceived Quality of Life (PQOL) Perceived self-efficacy (SEsx) (adapted measure) Vocational Integration Scale	Sig. (between groups): CIQ – <i>Difference between treatment and control</i> , medium effect. Sig. (within groups): PQOL – <i>Overall score</i> , small effect for treatment PQOL - small effect of treatment over control <i>overall</i> SEsx – <i>Overall</i> , small effect for treatment; <i>emotional</i> , medium effect for treatment; <i>cognitive</i> , small effect for treatment

Authors, year, country	Design	Sample source	Participants (N, characteristics / control)	Neuropsychological intervention, intensity and duration; Control and (follow up)	Psycho-social outcome measures used	Psycho-social outcomes: (Significant changes, Effect sizes)
						SEsx - small effect of treatment over control <i>overall</i> Vocational integration – Treatment participants more productive on discharge All gains maintained at follow up for treatment condition
Coetzer & Rushe (2005) UK	Cohort	Community multi-disciplinary neuro-rehabilitation service	N = 55, 63.6% male, mean age 38.9; Diagnosis: TBI 100%, 1.8% mild, 12.7% mod, 85.5% severe; Mean time since injury: 45.7 mths	Multi-disciplinary community rehabilitation; group and individual sessions. <i>Low intensity</i> : 2-3 hours a week, mean time in programme 10 mths (No follow up)	European Brain Injury Questionnaire (EBIQ)	Sig. (within groups): EBIQ (<i>ABI specific measure of wellbeing</i>) – <i>Overall score</i> (improved self and carer ratings), medium effect for self rating, small effect for carer rating
Curran et al. (2015) Australia	Cohort	Brain Injury Rehabilitation Community and home service	N = 47, 59% male, mean age 41; Diagnosis: TBI 45%, CVA 45%, other ABI 10%; Severity unknown; Mean time since injury: 3yrs	Individually tailored MDT approach, holistic perspective; group and individual with family involvement. <i>High intensity</i> : pre-post within 2 years, contact unclear (1-2 years variable follow up)	Mayo-Portland Adaptability Inventory (MPAI-4)	Sig. (within groups): MPAI – <i>Functional ability</i> : small effect on self report, carer reports medium effect, staff large effect MPAI – <i>Emotional adjustment</i> : small effect improvement on self report, staff report medium effect MPAI – <i>Community participation</i> : Medium effect on self and carer reports, staff report large effect

Authors, year, country	Design	Sample source	Participants (N, characteristics / control)	Neuropsychological intervention, intensity and duration; Control and (follow up)	Psycho-social outcome measures used	Psycho-social outcomes: (Significant changes, Effect sizes)
						Note. Of self and carer effects, only carer report of functional ability effect maintained at follow up
Goodwin et al. (2016) UK	Cohort	Outpatient neuropsychologica l rehabilitation service	N = 66, 62% male, mean age 31.6 / 42.24; Diagnosis: TBI 76%, other ABI 24%; Severity unknown Mean time since injury: 2.89 yrs / 2.84 yrs	Holistic integrated multidisciplinary approach, with individual family consultation and 6 weekly relatives peer group. <i>High intensity</i> : 12 weeks, 4 days/w then 12 weeks 're- integration' 2/3 days/w (No follow up)	The Dysexecutive Questionnaire self (DEX) and informant (DEX-I) The Modified Carer Strain Index (CSI)	Sig. (within groups): DEX – <i>Behavioural / emotional</i> : self and carer medium effect DEX – <i>Metacognitive</i> : self medium effect DEX – <i>Executive function</i> : self and carer medium effect CSI – <i>Time / Practical</i> : medium effect CSI – <i>Personal/Emotional</i> : medium effect
Goranson et al. (2003) Canada	Non- randomised controlled study	Outpatient brain injury clinic	N = 63 (42/21), 43/38% male, mean age 34.7 / 36.6; Diagnosis: TBI 100%; 38.1% /52.4% mild, 51.9% / 47.6% mod. Mean time since injury: 12.10 mnths / 13.48 mnths	Multidisciplinary programme of variable length, naturalistic tasks alongside cognitive rehabilitation – controlled environment: Group and individual therapies. <i>High intensity</i> : 4 days a week, mean duration in programme 4 months (range 1-7m) (No follow up)	Community Integration Questionnaire (CIQ)	Sig. (between groups): CIS – <i>Overall</i> intervention showed medium effect over control CIS – <i>Home integration</i> , intervention showed sig. improvement, control showed non. sig. decline. No other sig. findings.

Authors, year, country	Design	Sample source	Participants (N, characteristics / control)	Neuropsychological intervention, <i>intensity and duration;</i> <i>Control and (follow up)</i>	Psycho-social outcome measures used	Psycho-social outcomes: (Significant changes, Effect sizes)
Holleman et al. (2016) Netherlands	Non- randomised controlled trial	Intensive neuro- rehabilitation centre	N = 75 (42/33), 64.3/60.6% male, mean age: 43.3/40.7; Diagnosis: TBI 43/45%, stroke 21/15%, other ABI 36/40%; severity unknown. Mean time since injury: 7.9 / 6.9 yrs	Holistic multidisciplinary scheduled programme: fixed groups sessions plus a separate family group. Family group every 2 weeks and facilitated 'presentation' from patient to family. <i>High intensity:</i> 14 weeks, 4 days/w plus 2 week break. (No follow up)	Symptom Checklist-90 (SCL-90) Beck Depression Inventory (BDI-II), Hospital Anxiety and Depression Scale (HADS), State-Trait Anxiety Inventory (STAI-form Y) Quality of Life in Brain Injury (QOLIBRI)	Sig. (between groups): SCL-90 – Large effect for treatment over control 'Depression' (derived from HADS and BDI) – Large effect for treatment over control 'Anxiety' (derived from HADS and STAI- form) – Large effect of treatment over control QOLIBRI – Medium effect of treatment over control
Malec (2001) USA	Cohort	Comprehensive day treatment programme	N = 96, 73% male, mean age: 34.2; Diagnosis: TBI 72%, CVA 19%, other ABI 9%; 7% mild, 7% mod, 82% severe, 4% unknown; Mean time since injury: 4.6 years	Holistic comprehensive multidisciplinary programme: individualised, daily groups and individual therapy; work trail component and family involvement. <i>High intensity:</i> 5 days a week, average duration 189.5 days (1 year follow up)	Mayo-Portland Adaptability Inventory (MPAI) Goal attainment scaling (GAS) Independent living scale (ILS) Vocational Independence scale (VIS)	Sig. (within groups): MPAI (<i>ABI specific measure of wellbeing</i>) – Large effect of treatment pre to post GAS – 81% of 552 goals met (no statistical analysis) MPAI scores correlated with ILS and VIS at one-year follow up.
Ownsworth et al. (2000) Australia	Cohort	ABI support association newsletter and support requests	N = 21, 71% male, mean age 33.5; Diagnosis: 76% TBI, 5% stroke, 9% other	Group intervention integrating cognitive rehabilitation, CBT and social skills training – "self awareness model".	Head injury behaviour scale (HIBS) – self and relative Self regulation skills interview (SRSI)	Sig. (within groups): HIBS – relatives scores showed a large effect (improved emotional and behavioural problems)

Authors, year, country	Design	Sample source	Participants (N, characteristics / control)	Neuropsychological intervention, intensity and duration; Control and (follow up)	Psycho-social outcome measures used	Psycho-social outcomes: (Significant changes, Effect sizes)
			ABI; 76% severe, 10% mod, 14% mild. Mean time since injury: 8.6 years	<i>Low intensity</i> : 16 weeks, 1 x 90 minute session each week. (6 month follow up)	Sickness impact profile (SIP)	SRSI – significant improvement on “emergent awareness”, “anticipatory awareness”, “strategy selection” and “effects of strategies” indices – maintained at follow up (effect sizes not known) SIP – significant improvement on “social interaction”, “alertness behaviour”, “emotional behaviour” and “communication index” (effect sizes not known) Findings from SRSI and SIP maintained at follow up
Rasquin et al. (2010) Netherlands	Cohort	Outpatient cognitive rehabilitation programme	N = 27, 52% male, mean age 49.5; Diagnosis: Stroke 33%, TBI 18%, SAH 11%, other ABI 37%; severity unknown; Mean time since injury: 1.9 yrs * carer rated	Cognitive and social skills focussed group intervention plus two individual sessions and incorporating 1 session of family involvement. <i>Low intensity</i> : 16weeks at 2.5 hrs/w (6 month follow up)	Goal Attainment Scaling (GAS) Frenchay activities index (FAI) Stroke-adapted Sickness Impact Profile (SA-SIP30) Cognitive failures questionnaire (CFQ) Community Integration Questionnaire (CIQ) *Carer strain index (CSI) *Utrecht Coping List (UCL)	Sig. (within groups): GAS (<i>mean goal attainment scores</i>) – A large effect from pre to post was maintained at follow up FAI (<i>activities of daily living</i>) – significant effect between discharge and follow up, size unreported. Not sig. QoL (SA-SIP30), CFQ, CIQ, CSI, UCL

Authors, year, country	Design	Sample source	Participants (N, characteristics / control)	Neuropsychological intervention, intensity and duration; Control and (follow up)	Psycho-social outcome measures used	Psycho-social outcomes: (Significant changes, Effect sizes)
Rath et al. (2003) USA	RCT	Outpatient neuropsychologica l rehabilitation programme	N = 46 (27/19); 38% male, mean age 43.6; Diagnosis: TBI 100%; severity: 45% mild, 18% mod, 32% severe, 5% unknown; Mean time since injury: 48.2 mths	Group format 'innovative' problem orientated/solving, fixed programme, focussed on emotional and cognitive processes. Compared to 'conventional' NR cog rehab and psycho- social rehab in group. <i>Low intensity:</i> Both 24 weeks, 2 hrs/w vs 2-3 hrs/w (6 month follow up)	Sickness Impact Profile (SIP) – <i>Recreation and Social interaction composite scores only</i> Community integration questionnaire (CIQ) Problem Checklist (PCL) Brief Symptom Inventory (BSI) Rosenburg self-esteem scale (RSES) Problem Solving Inventory (PSI) Problem Solving Questionnaire (PSQ), Problem Solving Role- play test (PSRPT)	Sig. (within groups): Treatment group: RSES – Small effect; PSI – Medium effect; PSQ – <i>Self regulation scale</i> , small effect PSRPT – Medium effect Conventional group: PCL – <i>Physical severity (self rating)</i> , small effect PCL – <i>Physical severity (other rating)</i> , medium effect PCL – <i>Cognitive severity (other rating)</i> , small effect PSQ – <i>Self-regulation (other rating)</i> , small effect Not sig. CIQ (both), Problem solving measures (conventional), SIP (both) All outcomes maintained at follow up
Svendsen et al. (2006) Denmark	Cohort	Centre for rehabilitation of Brain injury, day service	N = 143; 58% male, mean age 41.4; Diagnosis: TBI 27%, CVA 60%, other 13%; mean severity 'mod-severe'. Mean time since injury 1.2 years	Interdisciplinary holistic approach tailored to individual: Group and individual therapies <i>High intensity:</i> fourth month programme with daily attendance – close contact and monitoring for 8 months in community	European Brain Injury Questionnaire (EBIQ)	Sig. (between groups): EBIQ – Large effect overall compared to healthy control Sig. (within groups) EBIQ – Small effects on <i>somatic, cognitive, motivation, impulsivity, depression, communication and core scales</i> .

Authors, year, country	Design	Sample source	Participants (N, characteristics / control)	Neuropsychological intervention, intensity and duration; Control and (follow up)	Psycho-social outcome measures used	Psycho-social outcomes: (Significant changes, Effect sizes)
				(No follow up)		Relatives agreed on all scales except motivation – scored higher difficulties.
Wolters et al. (2010) Netherlands	Cohort	Outpatient cognitive rehabilitation programme	N = 110, 56.4% male, mean age 45.1; Diagnosis: CVA 45%, TBI 30%, other ABI 11.8%, multiple ABI 17.3%; severity unknown; Mean time since injury: 2.8 yrs	Holistic multidisciplinary individualised programme incorporating group and individual sessions. <i>Low intensity</i> : Average 1-3 hrs/w for 3-5 mths. (No follow up)	Utrecht Coping List (UCL) Life Satisfaction Questionnaire (LiSat-9) Stroke-Adapted Sickness Impact Profile (SA-SIP30)	Sig (within groups). Less <i>problem-solving</i> coping and more <i>passive</i> coping post group – contrary to hypothesis. Use of passive coping was found to be a predictor of lower quality of life (SA-SIP30 & LiSat-9)

Table 3. Risk of bias for observation studies

Study ref	Unbiased selection of cohort?	Selection minimises baseline differences in prognostic factors?	Sample size calculation ?	Adequate description of the cohort?	Adherence to intervention / exposure to treatment?	Validated method for ascertaining clinical outcomes?	Outcome assessment blind to exposure?	Adequate follow-up period?	Completeness of follow-up?	Analysis controls for confounding ?	Analytic methods appropriate ?
Brands et al. (2013)	Yes	N/A	No	Partially	No	Yes	Can't tell	Yes	Yes	Yes	Yes
Caracul et al. (2012)	Yes	N/A	No	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Cicerone et al. (2004)	No	No	No	Yes	Yes	Yes	Partially	N/A	N/A	Yes	Yes
Coetzer and Rushe (2005)	Can't tell	N/A	No	Yes	No	Yes	Can't tell	N/A	N/A	No	Yes
Curran et al. (2015)	No	N/A	Yes	Yes	Partially	Yes	No	Partially	No	Yes	Yes
Goodwin et al. (2015)	No	N/A	No	Partially	Yes	Yes	Can't tell	N/A	N/A	Yes	Yes
Goranson et al. (2003)	No	Yes	Yes	Yes	No	Yes	No	N/A	N/A	Yes	Yes

Study ref	Unbiased selection of cohort?	Selection minimises baseline differences in prognostic factors?	Sample size calculation?	Adequate description of the cohort?	Adherence to intervention / exposure to treatment?	Validated method for ascertaining clinical outcomes?	Outcome assessment blind to exposure?	Adequate follow-up period?	Completeness of follow-up?	Analysis controls for confounding?	Analytic methods appropriate?
Holleman et al. (2016)	Yes	Yes	No	Partially	Yes	Yes	Yes	N/A	N/A	Yes	Yes
Malec (2001)	Yes	N/A	No	Yes	Partially	Partially	No	Yes	Yes	Yes	Yes
Ownsworth et al. (2000)	No	N/A	No	Yes	Yes	Yes	Partially	Yes	Yes	Partially	Yes
Rasquin et al. (2010)	Yes	N/A	No	Partially	Yes	Yes	Yes	Yes	Yes	Partially	Yes
Svendsen et al. (2004)	Partially	No	No	Yes	Can't tell	Yes	Can't tell	N/A	N/A	Yes	Yes
Wolters et al. (2010)	No	N/A	No	Partially	No	Partially	Can't tell	N/A	N/A	Yes	Yes

Table 4. Risk of bias for randomised-controlled studies

Study ref	Sequence generation	Allocation concealment	Blinding	Attrition	Selective reporting	Other
Cicerone et al. (2008)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Rath et al. (2003)	Unclear risk	Unclear risk	High risk	High risk	Low risk	Low risk

Outcomes

Studies employed different outcome measure to examine the effectiveness of interventions - reflecting the lack of consensus within the field of neuropsychological rehabilitation as to how best to evaluate outcomes in ABI (Sohlberg & Mateer, 2001; Williams, Evans, & Wilson, 1999). In keeping with previous reviews in this area (Cattalani et al., 2010; Cicerone et al., 2011; Cullen et al., 2007; Geurtsen et al., 2010) results are presented underneath within conceptually similar groupings (levels of intensity) in order to evaluate the emerging evidence for those interventions. Effect sizes were extracted for statistically significant intervention outcomes and can be found in appendix E. Psycho-social outcomes are broken down into conceptually similar categories, for the purposes of this synthesis (as defined in the methodology): psychological wellbeing, community integration, quality of life, executive function and behavioural difficulties. The additional category of activities of daily living and goal setting was included in the low-intensity synthesis as these were conceptually dissimilar.

High intensity holistic neuropsychological rehabilitation

One RCT (Cicerone et al., 2008), three non-randomised controlled trials (Cicerone, Mott, Azulay, & Friel, 2004; Goranson, Graves, Allison, & Freniere, 2003; Holleman, Vink, Nijland, & Schmand, 2016) and five cohort studies (Caracuel et al., 2012; Curran, Dorstyn, Polychronis, & Denson, 2015; Goodwin, Lincoln, & Bateman, 2016; Malec, 2001; Svendsen, Teasdale, & Pinner, 2004) reported psycho-social outcomes of high intensity neuropsychological rehabilitation for ABI.

Characteristics of high intensity interventions

There was a general level of consistency in the *core* approach taken to high intensity neuropsychological rehabilitation. All of the interventions utilised the core elements of cognitive rehabilitation, therapeutic group milieu, and interpersonal / social rehabilitation; and all, with the exception of Goranson et al. (2003) and Svendsen et al. (2004) specified a recognised holistic model (Trexler, 2000). Five interventions incorporated a specific family intervention (Caracual et al., 2012; Curran et al., 2014; Goodwin et al., 2016; Holleman et

al., 2016; and Malec, 2001). Two interventions incorporated a work trial component (Cicerone et al., 2004; and Malec, 2001). Goodwin et al. (2016), Goranson et al. (2003), Holleman et al. (2016), Malec (2001) and Svendsen et al. (2004) incorporated multidisciplinary therapeutic components.

Programme duration was highly variable, six were discrete interventions ranging from 16 weeks to 24 weeks; whilst three were of non-defined with stated mean duration ranging from 4 to 6 months (Goranson et al., 2003; Malec, 2001), Curran et al. (2015) did not report the mean length of programme; one intervention included “close contact and monitoring of progress in the community” for a further eight months (Svendsen et al., 2004). The intensity of the interventions ranged from four to five days a week; whilst Goodwin et al. (2016) ran for 12 weeks at four days a week, before dropping intensity to 2-3 days a week for the second twelve weeks.

Outcomes of high intensity studies

ABI adapted psychological wellbeing outcomes

Five studies measured illness related wellbeing pre and post intervention; Caracuel et al. (2012) and Svendsen et al. (2004) used the *European Brain Injury Questionnaire* (EBIQ), which has been shown to be a reliable measure of outcomes follow ABI (Sopena, Dewar, Nannery, Teasdale, & Wilson, 2007); Malec (2001) and Curran et al. (2015) used the *Mayo-Portland Adaptability Inventory-22* (MPAI-22) which was specifically developed for an ABI population (Malec, Moessner, Kragness, & Lezak, 2000); and Holleman et al. (2016) used the generic Symptom Checklist-90 (SCL-90) (Derogatis & Cleary, 1977). In a well-designed cohort study with a small number of participants (N=18) incorporating 12-month follow-up, Caracuel et al. (2012) participant self-report and carer-reports indicated a *large effect* of rehabilitation, at follow up, in the *social and emotional regulation* domain, whilst carer reports also indicated *large effects*, at follow up, in the areas of *depressive mood* and *cognitive dysfunction*. Improvements in carer rating of *cognitive dysfunction* were statistically significant on post-rehab measures, indicating that effects became established over time. The authors hypothesised that this long term improvement may relate to the caregiver intervention module; this may also have influenced carer ratings of participant improvements in wellbeing. Svendsen et al. (2004) also reported self and carer ratings of

the EBIQ in their cohort study of 143 rehabilitation participants. Both self-reports and carer-reports indicated a large effect overall, compared to healthy controls, and *small effect* post-intervention in *somatic, cognitive, motivational, impulsivity, depression and core scales*. These results must be interpreted with caution due to a significant selection bias, the authors excluded 29.9% of the sample primarily because no 'close relative' was able to complete the EBIQ. Malec's (2001) cohort study reported a *large effect* pre to post treatment of 96 participants on the MPAL-22, showing that positive changes were most common in the areas of *participation in interpersonal activities, reduction in physical disabilities, and increased self-awareness and emotional self-regulation*. Lower scores on the MPAL-21 (greater wellbeing) correlated with increased ratings of independent living and vocational independence at 1-year follow-up. Curran et al. (2015) found *small effects* for *functional ability and emotional adjustment* post-treatment and *medium effects* for *community participation* on self-report; carers reported *medium effects* for *functional ability and community participation* post treatment. At follow up these effects were not maintained, with the exception of carer reports of improved *functional ability*. The strength of the evidence from this study is particularly limited due to the high rate of attrition and a lack of specificity regarding the duration, intensity and composition of the intervention. All four studies were limited by the lack of control, making it difficult to attribute gains to specific elements of the interventions. In a high quality non-blinded waiting-list controlled study of 75 participants, Holleman et al. (2016) reported a *large effect* of rehabilitation on general wellbeing, as measured by the SCL-90; however, the lack of follow up means that they were unable to report whether these gains were maintained over time.

Executive Functioning and behavioural

Two studies measured frontal-systems cognitive function related to behaviour and emotion-regulation; Caracul et al. (2012) reported improvements in this area using the Frontal Systems Behaviour scale (FrSBe; Grace & Malloy, 2001), with *large effects* at 1-year follow-up on self and carer reports of *apathy and executive function*, whilst carers also reported a *large effect* post discharge in the area of *disinhibition*, which was not found to be significant at follow up. Goodwin et al. (2015) utilised the Dysexecutive Questionnaire self-rating (DEX) and informant rating (DEX-I) (Wilson, Alderman, Burgess, Emslie, & Evans, 1996) pre and post intervention, in a cohort study of 66 rehabilitation participants. Self and carer ratings showed *medium effects* in *executive function and behavioural and emotional domain*; self ratings also

showed a *medium effect* post intervention in the *metacognitive* domain, which was not identified by carer ratings. The Goodwin et al. (2015) study must be interpreted with caution, as data was only available for 66 of 407 patients who completed during the period of evaluation, and no follow up data was reported.

Community Integration

Three studies evaluated community integration following rehabilitation using the Community Integration Questionnaire (CIQ), which was developed specifically to examine outcomes in ABI (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993). A non-randomised controlled trial of MDT delivered holistic rehabilitation for mild to moderate brain injuries (Goranson et al., 2003) compared CIQ outcomes for 42 treatment participants with 21 non-treatment controls. They found that the intervention showed a *medium effect* for community integration over controls. The treatment group showed a significant improvement in *home integration* whilst the controls showed a decline in this area. The individualised approach and non-discrete timescale of the intervention mean that it is difficult to interpret the active elements of this intervention, and there was no follow up to evaluate integration over time. Cicerone et al.'s (2004) non-randomised controlled trial (N=56) compared holistic rehabilitation with 'standard' individually delivered, multi-disciplinary (MDT) neuropsychological rehabilitation using the CIQ. They found a *large effect* on the CIQ for the holistic group and *medium effects* for the individual MDT group. When compared, the holistic group showed significantly improved outcomes for *home integration and productivity* over MDT. A flaw of this study was the lack of follow up data, and there was a systematic bias in treatment allocation, with control participants having suffered their injury more recently. An RCT with low risk of bias (Cicerone et al., 2008) subsequently compared holistic and standard MDT neuropsychological rehabilitation, with a 6 month follow up and well matched controls. This study did not replicate the significant main effects, for either treatment or control, of the prior study; however, there was a significant difference *between* the two groups, with a *medium effect* in favour of the holistic intervention. The difference in main effects in these studies could be related to the improved design of the latter; a significant difference between the two studies is that Cicerone et al.'s (2004) intervention included one day a week work placement, whilst Cicerone et al.'s (2008) intervention did not. Both studies consistently showed that holistic approaches performed better than individual MDT rehabilitation for CIQ outcomes.

Quality of life

Two studies investigated quality of life following rehabilitation. Utilizing the Perceived Quality of Life (PQOL; Patrick, Danis, Southerland, & Hong, 1988) Cicerone et al. (2008) found a *small effect* overall of holistic rehabilitation compared to standard MDT rehabilitation and a *small effect* for the holistic treatment condition. Holleman et al. (2016) used the disorder specific Quality of Life in Brain Injury (QOLIBRI; von Steinbüchel et al., 2010), finding a *medium effect* post-treatment over waiting list control.

The Holleman et al. (2016) study was unique amongst those included in the review, in that it reported standard psychological outcome measures pre and post treatment for anxiety and depression; finding *large effects* for both compared to controls. Goodwin et al. (2016) reported *medium effects* on measures of carer strain post-treatment; and Cicerone et al. (2008) reported improvements in perceived self-efficacy amongst participants post treatment.

Conclusions regarding high intensity holistic neuropsychological rehabilitation

There is evidence from one well designed waiting-list controlled study and four cohort studies of variable quality that holistic neuropsychological rehabilitation can be effectively improve illness related wellbeing after brain injury. Breakdown of these measures into components found that both participants and carers observed changes in areas of mood, cognition and self-regulation, and there is limited evidence from three studies which incorporated carer focused treatment protocols that these effects are maintained, and may even increase, over longer periods. Two cohort studies also provide evidence of improvements in executive function which showed changes in behavioural, emotional and cognitive function observed by both participants and carers.

Evidence from a well conducted RCT and two non-randomised controlled trials suggests that holistic neuropsychological rehabilitation is more effective than individually delivered MDT neuropsychological rehabilitation at enabling community integration following brain injury. The largest effect was reported in association with vocational trials, although studies without this component also showed improvement in home integration and vocational integration. Further evidence is required to establish if these outcomes are maintained at follow up.

There is limited evidence from individual studies that holistic rehabilitation may have broad psychological benefits on outcomes such as depression, anxiety, self-efficacy and quality of life. Taken together with the evidence from global illness related wellbeing measures this presents a strong case that holistic rehabilitation interventions can improve psychological wellbeing following ABI.

Low intensity holistic neuropsychological rehabilitation

One RCT (Rath, Simon, Langenbahn, Sherr, & Diller, 2003) and five cohort studies (Brands, Bouwens, Wolters Gregório, Stapert, & Van Heugten, 2013; Coetzer & Rushe, 2005; Ownsworth, McFarland, & Mc Young, 2000; Rasquin et al., 2010; Wolters, Stapert, Brands, & Van Heugten, 2010) reported psycho-social outcomes of low intensity neuropsychological rehabilitation for ABI.

Characteristics of low intensity interventions

All of the low intensity neuropsychological interventions incorporated cognitive rehabilitation, interpersonal / social rehabilitation and included group components. However, there was a larger amount of variability in the *depth* of the therapeutic milieu employed, compared to high intensity interventions. The three studies (Brands et al., 2013; Coetzer & Rushe, 2005; and Wolters et al., 2010) employing an individually-tailored MDT approach emphasised that group and individual components were available, however, only Brands et al. (2013) reported the balance of individual to group therapies; and in this study 12 of 26 participants elected to take only individual modules. Three studies (Ownsworth et al., 2000; Rasquin et al., 2010; and Rath et al., 2003) employed a group format throughout, suggesting a more consistent therapeutic milieu. Three interventions incorporated a specific family component; Brands et al., 2013; and Rasquin et al., 2010) included structured family sessions, whilst Coetzer & Rushe (2005) offered a monthly 'drop-in' session.

Programme duration varied depending on the approach taken. The three individually tailored MDT interventions were offered on the basis of patient need and clinician judgement; the mean duration ranged from four to ten months. Two of the group format

interventions ranged were delivered for 16 weeks (Ownsworth et al., 2000; and Rasquin et al., 2010), whilst both arms of the Rath et al. (2003) RCT ran for 24 weeks. The intensity of all interventions ranged from 1 to 5 hours a week for non-discrete programmes, and from 90 minutes to 3 hours a week for discrete groups.

Outcomes of low intensity studies

ABI adapted psychological wellbeing outcomes

Two studies measured illness related psychological wellbeing (Coetzer & Rushe, 2005; and Rath et al., 2003). Coetzer & Rushe (2005) reported an individually tailored MDT intervention (N=56) which was measured using the EBIQ found that both participants and carer reported *small effects* of rehabilitation post treatment. *Moderate effect* sizes were found on carers reports of participants less than two years post-injury, whilst participant reports were consistent across the whole sample. This study was limited by a lack of follow up, variable implementation of the intervention and limited analysis of the outcome, which was only reported as a global measure. In a non-blinded RCT comparing an 'innovative' treatment group, which focussing emotional self-regulation and problem solving, with a 'conventional' group, employing cognitive remediation and psycho-social rehabilitation, Rath et al. (2003) utilised the Problem Checklist (PCL; Kay, Cavallo, Ezrachi, & Vavagiakis, 1995) and Brief Symptom Inventory (BSI; Meachen, Hanks, Millis, & Rapport, 2008) to investigate symptom complaints across two treatment conditions. There were no significant effects on either measure in the 'innovative' treatment group; however, participants in the 'conventional' group reported a *small effect* on the *physical severity* scale of the PCL, and carers reported a *moderate effect* on the *physical severity* scale and a *small effect* on the *cognitive severity* scale of the PCL; which were maintained at 6 month follow up. This study did not compare the relative effect between treatment condition and lacked detailed procedural reporting, limiting further analysis of the effective treatment components. Rath et al., (2003) separately measured self-esteem in both treatment conditions using the Rosenberg self-esteem scale (RSES; Rosenberg, 1965); participants in the 'innovative' treatment condition showed a *small effect* improvement; whilst those in the 'conventional' condition did not show a significant change.

Executive Functioning and behavioural

Four studies reported specific neuropsychological outcomes related to functioning following brain injury. In a well designed cohort study (N=21) of a discrete group intervention, Ownsworth et al. (2000) investigated self-awareness of deficits using the Head Injury Behaviour Scale (HIBS; Godfrey, Partridge, Knight, & Bishara, 1993); and self-regulation using the Self regulation skills interview (SRSI; Ownsworth, McFarland, & Young, 2000). On the HIBS, carers rating showed a *large effect* indicating an observable change in *emotional and behavioural difficulties*; however, an improvement in participant scores was not statistically significant. The SRSI with participants showed statistically significant improvements post treatment on indexes of *emergent awareness, anticipatory awareness, strategy selection and effects of strategies*, changes to the *motivation* index were not significant. Findings on the SRSI were maintained at follow up. Rath et al.'s (2003) RCT examined *problem solving* using the Problem Solving Inventory (PSI; Heppner, 1988), the Problem Solving Questionnaire (PSQ; Rath, Simon, Langenbahn, Sherr, & Diller, 2000) – *clear thinking* and *emotional self-regulation* subscales only; and the Problem Solving Role-Play Test (PSRPT; Rath et al., 2000). Participants in the 'innovative' problem-orientated condition showed improvements on the PSI, *medium effect*, which were substantiated by a *small effect* in *clear thinking* and a *medium effect* in *self-regulation* on the PSQ; and a *medium effect* on the PSRPT. The only effect for this construct reported in the 'conventional' condition was a carer-reported *small effect* on the *self-regulation* scale of the PSQ. These improvements were maintained at 6 month follow up. Two cohort studies (Brands et al., 2013; and Rasquin et al., 2010) measured *cognitive errors* using the Cognitive Failures Questionnaire (CFQ; Broadbent, Cooper, FitzGerald, & Parkes, 1982) and found *no significant changes* in this outcome following a non-discrete individually-tailored MDT intervention or a 16 week group intervention respectively.

Quality of life

Illness-related quality of life was investigated by five of the six low intensity studies. Three cohort studies (Brands et al., 2013; Rasquin et al., 2010; and Wolters et al., 2010) used the Stroke-adapted Sickness Impact Profile (SA-SIP30); and two studies (Ownsworth et al., 2000; and Rath et al., 2003) used the standard Sickness Impact Profile (SIP), which has been validated in an ABI population (Fleming, Strong, Ashton, & Hassell, 1997). Wolters et al., (2010) also used the generic Life Satisfaction Questionnaire (LiSat-9) (Fugl-Meyer, Bränholm, & Fugl-Meyer, 1991). *No significant changes* were reported pre to post in the

three cohort studies using the SA-SIP30 (Brands et al., 2013; Rasquin et al., 2010; and Wolters et al., 2010). Ownsworth et al.'s (2000) cohort study reported *significant improvements* on the SIP as a result of their "self awareness" model discrete group intervention (N=21), which were maintained at follow up; whilst Rath et al. (2003) *did not find significant effects* on the SIP in either treatment condition. Ownsworth et al. (2003) suggested that improvements on the SIP may have been related to improved self-regulation; however this was not statistically evaluated. It is of note that the Ownsworth et al., (2000) study recruited participants using advertisement rather than utilising a clinical referral procedure, which may have biased the population towards a more self-motivated population. Wolters et al. (2010) did not report the main effect of treatment on the SA-SIP30 and LiSat-9. The lack of control conditions in the above studies mean that it is not possible to evaluate the relative effectiveness of the different interventions.

Community Integration

Two cohort studies (Brands et al., 2013; and Rasquin et al., 2010) and one RCT (Rath et al. 2003) reported community integration outcomes using the CIQ; and *no significant effects* were reported for low intensity interventions.

Activities of daily living and personalised goals

Along with the outcomes listed above, the two cohort studies (Brands et al., 2013; and Rasquin et al., 2010) also measured activities of daily living (ADL) using the Frenchay Activities Index (FAI; Schuling, De Haan, Limburg, & Groenier, 1993); carer strain using the CSI; *coping* styles using the Utrecht Coping List (UCL; Schreurs, van de Willige, Tellegen, & Brosschot, 1993); and personalised *goal attainment* using Goal Attainment Scheduling (GAS; Kiresuk & Sherman, 1968). Rasquin et al.'s (2010) well designed cohort study (N=27) of a discrete group intervention reported a *large effect* for goal attainment, which was *maintained* at 6-month follow up; Brands et al.'s (2013) individualised non-discrete MDT intervention (N=26) reported *significant effects* post intervention which were maintained at 6-month follow up; however, the size of the effect was not reported. Both of these studies reported overall mean scores on GAS with individuals setting differing numbers of goals, which may misrepresent how many individuals benefited from the interventions overall. Rasquin et al. (2010) found a *significant improvement* in ADL's amongst their participants from post treatment to 6-month follow up using the FAI. No significant change was reported on the FAI by Brands et al. (2013). Neither Brands et al. (2013) nor Rasquin et al. (2010) demonstrated a significant effect upon

carer strain (using the CSI) or *coping styles* (using the UCL). In a cohort study of a non-discrete individualised MDT programme, Wolters et al. (2010) measures coping using the UCL and found that following rehabilitation participants reported significantly *less* problem-focussed coping and *more* passive coping. A post-hoc regression analysis found that *increased* passive coping was a predictor of *lower* quality of life.

Conclusions regarding low intensity holistic neuropsychological rehabilitation

There is limited evidence from one low quality RCT and one cohort study that low intensity rehabilitation programmes can improve illness related wellbeing following brain injury. Participant ratings in these two studies were generally corroborated by carer ratings, although effect sizes were higher from carers than from participants. These findings were inconsistent, with only an individualised non-discrete MDT treatment and the conventional treatment condition in the RCT showing improvements on general areas wellbeing; whilst a specially adapted 'problem-orientated' approach did not lead to general outcomes but did improve self-esteem.

Studies looking at specific areas of cognition and wellbeing used different measures to examine similar cognitive constructs. Significant improvements in self-regulation were seen in one RCT and one cohort study, which were again corroborated by carer ratings; these studies were group-based discrete interventions. Improvements in problem solving were reported in the 'problem-orientated' condition of the RCT, however this was not found in 'conventional' treatments, and one cohort study of non-discrete individualised MDT rehabilitation found evidence of reduced problem-focused coping. Evidence from two cohort studies suggests that low intensity interventions do not influence cognitive errors themselves.

There is not enough evidence to establish whether low intensity holistic approaches can improve quality of life following brain injury. Four of the studies in this review did not show significant effects post treatment or at follow up. One cohort study showed significant effects of a manualised "self-awareness" model treatment (Ownsworth et al., 2000) upon quality of life, however this may relate to the specific treatment approach or population sample. There is limited evidence from one study that quality of life after ABI may be related to coping styles.

There was no evidence for the effectiveness of low intensity interventions at improving community integration or carer strain. Two cohort studies found consistent evidence of improvements to patient centred goals, which were maintained at six-month follow up. The stronger evidence was found in the cohort study with a discrete group approach by Rasquin et al. (2010), who also found limited evidence from one cohort study to suggest potential longer term benefits to activities of daily living.

Low intensity holistic neuropsychological interventions showed a high range of variability across studies in terms of design quality, intervention approach and outcomes examined and therefore it is not possible to come to a strong conclusion regarding their overall effectiveness. However; there is sufficient evidence to suggest that specific approaches can be effective, particularly at improving the specific psycho-social outcomes they are designed to target. Discrete group interventions appear to offer greater potential for improvement and larger effect sizes when compared to non-discrete MDT individualised approaches.

Discussion

Clinical implications

No previous review has specifically examined outpatient forms of holistic neuropsychological rehabilitation, and this is the first review to include low intensity forms of outpatient holistic neuropsychological rehabilitation. This is of particular importance, as the longer term needs of an outpatient ABI population are qualitatively different to those of inpatient acute and post-acute ABI patients (Fleminger, 2008, 2010) shifting from immediate physical need to the psycho-social sequelae.

In keeping with the findings of previous reviews, high intensity interventions may offer longer term benefits in areas such as community integration and executive functioning (particularly self-regulation and problem solving) (Cicerone et al., 2011; Kim and Colantonio; 2010). This review also adds support to the suggestion that high intensity rehabilitation can improve psychological wellbeing following ABI; however, as found previously (Fann, Hart, & Schomer, 2009), few studies in this area specifically examine improvements in mood. The evidence for low intensity interventions is much less clear. This area of research is emerging alongside the shifting priorities of community

neuropsychological rehabilitation teams, which are moving towards more functional and longer term outcome following ABI – in keeping with shifting global priorities for health (WHO, 2001). In contrast to the high intensity studies reviewed, low intensity studies showed a greater variance in approach, targeted outcomes and research quality. This finding mirrors the state of post-acute inpatient rehabilitation in previous decades (Carney et al., 1999; Chesnut et al., 1999; Cicerone et al., 2005). This review suggests that low intensity interventions for the chronic phase of psycho-social adjustment post ABI may prove an effective tool for services seeking to meet the diverse needs of this population; however, it appears that low intensity interventions may have fewer general psycho-social benefits for patients and carers. The most consistent evidence was for improvements in self-efficacy and meeting patient centred goals. It has been suggested that Goal Attainment Scheduling (GAS) is not an outcome, rather a measure of expectation in rehabilitation (Turner-Stokes, 2009); however GAS may also enable clinically meaningful changes in other areas of function (Fisher, 2008). Brands et al. (2013) and Rasquin et al. (2010) suggested that the benefits of patient centred low intensity interventions may not be reflected in more generic outcome measures. This may match well with the immediate needs of ABI patients seeking to solve problems and meet their needs in the community. Potentially, these less resource intensive interventions may be useful as a *refresher* or *as needed* intervention for patients with specific psycho-social adjustment needs over the course of their lifetime. As previously suggested by Turner-Stokes et al. (2005), services need to balance the level of intensity of interventions with the specific needs of ABI patients.

Limitations of review

The lack of a defined pre-registered review protocol introduces a potential source of bias in this study. As outcomes of interest and inclusion criteria were not pre-specified, this opens the possibility that inclusion criteria and outcomes of interest may be modified without this being explicit to the reader. Further reviews in this area should seek to define and pre-register review protocol to mitigate this limitation. The broad scoping approach taken to including all 'psycho-social' outcomes in this study meant that primary outcomes were not modified, however, this broad approach limited the specificity of the findings. Future studies would benefit from focussing on a narrower primary outcome once a greater number of studies are published in this area.

This review took an inclusive approach to a broad area of clinical practice which seeks to meet the diverse psycho-social needs of a heterogeneous population. It sought to identify examples of both 'best' practice and 'realistic' practice in neuropsychological rehabilitation. In doing so, some papers may have been of too low quality to reach meaningful conclusions on their own; however, the current synthesis aims to establish the best available evidence available at this time.

The minimal definition of 'holistic' interventions may have included some studies in which the *therapeutic milieu* was not as clearly present (e.g. Brands et al., 2013). In taking this approach this review sought to utilise the best evidence which was already available in order to identify effective approaches. As the evidence for high intensity interventions neuropsychological rehabilitations is more established, a more specific examination of all (both holistic and non-holistic in form) low intensity approaches to meet the psycho-social needs of this population may have yielded more evidence.

Previous reviews of rehabilitation in ABI have consistently cited the lack of high quality RCT's in this area (Cattalani et al., 2010; Cullen et al., 2007; Teasell et al., 2007), which limits the strength of the evidence base, and reliability of treatment recommendations. This is also a key limitation of the present review. The reasons for this absence of high quality evidence include; small numbers, heterogeneity in samples and outcomes; and the ethical constraints of seeking consent from patients with limited capacity or of randomising patients to waiting-list or standard conditions (Turner-Stokes, 2008). Turner-Stokes (2008) suggests reviews in this area should seek to synthesise evidence from multiple sources in order to build a broader argument for the effectiveness of rehabilitation. It is hoped that this review will contribute to the emerging body of evidence for holistic neuropsychological rehabilitation by collating the available evidence for outpatient interventions, identifying gaps which would benefit from future research.

Suggestions for future research

The process of reviewing this body of literature identified a wealth of conference abstracts and research posters suggesting that low intensity holistic-type neuropsychological rehabilitation is much more common in practice than the number of published peer-reviewed articles would represent. A clear research recommendation which follows from

the above discussion of limitations in this area, is that services and individuals are not put off by the difficulties of producing 'high-quality' empirical research in this area. Rather, it is recommended that clinicians regularly seek to audit and publish data, particularly if it relates to the kinds of low intensity, adapted interventions which may be representative of current practice. The Holleman et al. (2016) paper, reviewed here, utilised a non-blinded 'waiting list controlled' design, which allocated patients to treatment on the basis of time of referral. Utilising this design over the cohort studies which predominate in the current review would allow for deeper investigation into the efficacy of clinically led, retrospectively evaluated clinical interventions. Whilst there may be ethical considerations regarding patients waiting for essential treatment, it is likely that many outpatient services hold clinical waiting lists in routine practice which would be well matched demographically with clinical treatment samples. In addition, the interventions which used discrete designs, reporting detailed descriptions of the interventions and collected routine follow up data provided most insight into the efficacy of community rehabilitation to meet psycho-social the needs of a chronic ABI population. Interventions which used both participant and carer measures showed a high level of consistency and which enhanced the reliability of findings, whilst providing broader psycho-social insight. Carer ratings should be included, where possible, to aid analysis.

More research is also needed to better understand the 'active ingredients' of both high and low intensity holistic neuropsychological rehabilitation. Given the complex and multifaceted nature of holistic neuropsychological rehabilitations, where possible, future RCT's and controlled studies in this area should seek to control as many treatment variables as possible and limit interventions to the core elements under investigation, rather than 'adding in' additional trials such as vocational rehabilitation. Discrete group-based low intensity interventions appeared to be more effective than long-term individually-tailored approaches for chronic difficulties in ABI; and group interventions have been shown to be twice as likely to effect change in self-identity following ABI than individually based therapies (Ownsworth & Haslam, 2016). Future research should seek to identify the interpersonal group-dynamics which best facilitate effective change in ABI.

Summary

This review suggests that high intensity forms of outpatient neuropsychological rehabilitation are effective at improving psycho-social outcomes. Low intensity forms of outpatient neuropsychological rehabilitation appear to offer a less favourable alternative to supporting psycho-social adjustment in the community at present. Low intensity interventions may however be effective in targeting specific psycho-social difficulties such as self-regulation, problem solving and meeting patient-centred goals.

Where possible community neuropsychological rehabilitation teams should be offering high intensity interventions to meet the long-term psychological and social needs of a community ABI population; however, where specific needs and goals are identified low intensity interventions may offer a less resource intensive option. Such interventions should be routinely audited and their outcomes published in order that future reviews of low intensity holistic neuropsychological rehabilitation can better establish the efficacy of this emerging practice.

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Chapter 2: Empirical Journal Article

Narratives of self-identity and group rehabilitation after brain injury

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Abstract

Introduction: The personal consequences of acquired brain injury (ABI) are intrinsically linked to and individuals' social, emotional and functional context. Changes in self and group identity have been suggested to be fundamental to adaptation following ABI and underpin evidence-based neuropsychological rehabilitation. However, little is known about how these processes of identity change following ABI and throughout the rehabilitation process. This study explores key turning points in the self-narratives of individuals with ABI in order to better understand the clinical and contextual factors which influence their rehabilitation.

Method: A 'holistic-content' narrative methodology was employed to explore the post-acute adjustment and rehabilitation narratives of 11 individuals following ABI. Three-dimensional analysis of *interaction*, *continuity* and *situation* was used to examine individuals' personal reflections of identity changes across their illness experience; and cross-case comparisons identified common transformational themes.

Results: Themes of 'Rehabilitation focus and psychological distress', 'Reclaiming efficacy in valued life domains', and 'Social comparisons: inclusion and exclusion' were identified. Each representing a continuum of personal and social understanding along which people moved during their rehabilitation.

Discussion: Key processes of identity transformation are discussed with respect to participant narratives. Illness identity may be co-constructed in the context of early treatment experiences, and appears to influence post-acute rehabilitation focus; whilst pre-injury values and self-identity guided approaches to re-establish efficacy. These processes were influenced by clinical, social and group interactions.

Key words: Acquired Brain Injury; Neuropsychological Rehabilitation; Self identity; Social identity; Narrative.

Introduction

Acquired brain injury (ABI), either as a result of an external traumatic event or a physiological event, is a condition which transforms the lives of individuals and those around them. ABI is typically characterised by symptoms such as motor impairments, attention deficits, speech difficulties, memory loss and emotional lability (Jones, Jetten, Haslam, & Williams, 2012; Ownsworth, 2014; Scottish Intercollegiate Guidelines Network [SIGN], 2013). The neurological damage resulting from ABI often leads to neuro-behavioural changes, emotional disorders and significant social disruption (Sohlberg & Mateer, 2001; Williams & Evans, 2003). Survivors of ABI are at a high risk of developing mood disorders, such as anxiety and depression following hospital discharge (De Wit et al., 2008; Gould et al., 2011; Van Reekum, Bolago, Finlayson, Garner, & Links, 1996); which are often more disabling than neuro-physical factors (Fleminger, 2008; Fleminger, Greenwood, & Oliver, 2006)

For many years the focus of ABI treatment and research was on remediation of cognitive impairments in areas such as attention, memory and executive function (King & Tyerman, 2003). This approach is moderately effective when targeted at specific deficits (Cicerone et al., 2011; Rohling, Faust, Beverly, & Demakis, 2009); however, there is a lack of clinical consensus regarding whether these are the mechanisms which drive successful rehabilitation outcomes in the longer term (Sohlberg & Mateer, 2001; Williams, Evans, & Wilson, 1999). In a systematic review of broader outcomes of neurological rehabilitation (NR), Carney et al. (1999) suggested that a greater focus should be placed on those outcomes most important to patients and their families.

Qualitative researchers have attempted to shift the focus of research by examining the factors that are most pertinent to successful recovery for brain injury survivors. For example, in Nochi's (2000) study, examining narratives of 'successful' coping and adjustment, survivors of ABI placed self-identity as central to their rehabilitation experience. A recent meta synthesis of 23 qualitative research studies exploring the experience of recovery and outcome following traumatic brain injury (Levack, Kayes, & Fady, 2010) identified eight inter-related themes of key importance to ABI survivors. Six of these eight themes were related to the survivors' identity, including the loss and reconstruction of personal identity, the loss of connection with and control of one's body, and the loss and reconstruction of a place in the world. This is in clear contrast the

traditional approach of NR research, which focussed predominantly on cognitive impairments. Emerging from the qualitative literature is a complex picture of ABI as a condition which affects not only the brain but the self-in-context.

Practitioners of 'holistic rehabilitation' have argued that cognitive factors cannot be separated from the social, emotional and functional context within which survivors of brain injury seek to establish their personal rehabilitation (Ben-Yishay, 2000; Prigatano, 1999). Holistic interventions incorporate group therapies that emphasise reflective meta-cognitive and emotion-regulation skills alongside traditional NR, aiming towards gradual "reconstitution of the identity of patients following TBI" (Ben-Yishay, 2008). In a randomised controlled trial (RCT) of intensive (15 hours a week for 12 weeks) NR, holistic rehabilitation patients were "twice as likely to make significant gains" than with traditional multidisciplinary rehabilitation (individually focused physical therapies and cognitive rehabilitation). The holistic group also showed greater improvements on measures of perceived quality of life, community integration and self-efficacy (Cicerone et al., 2011; Cicerone et al., 2008). This research context has also underpinned the development of ABI rehabilitation models which integrate psycho-social factors alongside the traditional neuro-cognitive focus (Gracey, Evans, & Malley, 2009; Ownsworth, 2014; Williams & Evans, 2003). Each of these models places self-identity at the heart NR for ABI.

A recent review by Walsh, Fortune, Gallagher, & Muldoon (2014) concluded that an under attention to social factors is the most prominent weakness of contemporary neuropsychology. Synthesising contemporary neuropsychological research, they highlight the interrelationship of neurological functioning and social cognition, arguing that both personal and social identity are underpinned by the same neural machinery. Traditionally, psychological research into coping with identity change has focussed on personal resources or traits such as 'resilience'. For example, Lazarus and Folkman's (1984) influential *transactional model* focusses on the individual's appraisal of perceived threat and evaluation of their personal resources for managing that threat. Within this framework social 'support' is characterised as a personal resource, rather than an integral part of that *self* which both perceives and attempts to mitigate stressors in response to life transitions.

By contrast, the social identity approach, which incorporates social identity theory (SIT; Tajfel and Turner, 1979) and self-categorization theory (SCT; Turner, 1985), suggests that individuals' derive their self-identity from group membership, and propose that group

identification can influence wellbeing through shifting perceptions of symptoms, norms and shared coping and social support (Haslam, Jetten, Postmes, & C. Haslam, 2009). Social connectedness and social supports can be associated with both positive and negative outcomes for health and wellbeing⁴, dependent upon the *quality* of social relationships, the shared group norms (such as prominent coping strategies) and the extent to which an individual *feels* connected to a particular group (Jetten, C. Haslam, Haslam and Dingle, 2014). Jetten et al. (2014) argue that a focus on the process through which shared identity affects health and well-being is required if we are to understand why social support can be beneficial in some instances, and detrimental in others.

Iyer, Jetten and Tsivrikos (2008) have developed the Social Identity Model of Identity Change (SIMIC), which has been used in a range of clinical, educational and workplace settings to examine the role which social identity and self categorisation play in life-changing transitions. Central to this model is the idea from SIT that we derive our self-concept largely from the social groups we belong to. The extent to which we feel connected (self-categorise) to a particular group influences the extent to which we *psychologically internalise* that group's norms of behaviour and shared social identity. At times of crisis both personal and group identities are affected and both positive and negative changes must be negotiated in this transition, attenuated through personal and social resources. For example, following a bereavement, a particular family, community or religious social identity-grouping may prescribe set rituals or supportive group practices, which serve to help the individual or group negotiate their changing circumstances. Unexpected events, such as acquiring a brain injury, typically lack set social rituals, and this can have a negative effect on wellbeing. SIMIC has been used in an ABI population to demonstrate that maintaining group membership and building new groups can enhance wellbeing (Douglas, 2012; C. Haslam et al., 2008). Stronger brain injury group identification has also been indicated as a mediator of personal and social changes following ABI (Jones et al., 2011).

Emerging in contemporary neuropsychology is a field of ABI research which seeks to investigate the complex interwoven factors underpinning NR. Interventions seeking to facilitate both adaptation to the effects of ABI and identity transformation are beginning to be developed; however, a key challenge for researchers is to understand the mechanisms

⁴ For a meta-analytical review of the relationship between social support and health outcomes see Schwarzer and Leppin (1991).

which underpin neuropsychological rehabilitation within this framework (Ownsworth, 2014). It has been suggested that studies focussing on the early adjustment period following hospital transition may provide more scope to understand the processes of adjustment over time, as well as the antecedents and consequences of poor adjustment (Turner et al., 2007). In particular, there is limited research examining the personal experiences of ABI survivors following their transition from hospital (Cullen et al., 2007; Turner et al., 2008) and none examining the experience of group neuropsychological rehabilitation (Fraas & Calvert, 2009; Sarajuuri, 2006). Further investigation of early adjustment is of particular importance due to the high rates of mood disorders following discharge (De Wit et al., 2008; Gould et al., 2011) and because many survivors of ABI do not receive routine follow up following discharge from hospital. In a Scottish prospective cohort study which followed up 489 survivors of mild to severe head injury after one year, Thornhill et al. (2000) found that only 47% of disabled survivors had been seen in hospital post discharge, whilst only 28% reported having received input from rehabilitation. Whilst the majority of NR research has looked at intensive forms of inpatient rehabilitation, the early adjustment experiences of many with ABI are likely to be experienced outside of this treatment context.

This broad body of research demonstrates that adjustment following ABI involves a complex interplay between neuro-cognitive, psychological and social factors, with identity transformation at its core. The present research explores the adjustment and rehabilitation narratives of ABI patients who have attended a community-based 'low-intensity'⁵ NR group; examining retrospective accounts of their personal experience of rehabilitation in order to understand the *active process* of identity transformation as it unfolds from the survivor's perspective. Understanding the processes of early adjustment and survivor experiences of identity transformation may lead to valuable insights, with clinical and research implications for reducing psychological distress and facilitating adjustment following ABI.

Method

This study used a narrative approach to explore how eleven survivors of ABI construct their identity following their initial treatment and throughout the process of rehabilitation. A

⁵ Low intensity: No more than one day per week.

narrative methodology was chosen because it allows an analysis of participant's identity through the stories they construct in relation to their illness (Bruner, 1990; Kirmayer, 1992; Mattingly & Garro, 2000).

A focus on both the content and the process (Labov, 1972) of participant storytelling allows an exploration of how their narrative has developed *temporally* through moments or 'turning points' in the narrative (Lieblich, 1998), and *contextually* in relation to the meaning this holds for them in key areas of their lives. In the context of acquired brain injury this might include, for example, their relationships with family and care providers. By examining personal stories, we can access 'snapshots' of how these interpretive filters come to bare on the rehabilitation process.

The data were collected using a semi-structured interview process, where the participants were guided to reflect on their experiences at various time points relative to their acquired brain injury. The narratives were then analysed by the lead researcher, with a focus on emergent themes and narrative processes - seen through the multiple lenses of language, context and 'moments' of re-construction (McCormack, 2004). A summary of this analysis was then shared with participants for member validation (Elliott, Fischer, & Rennie, 1999; McCormack, 2004).

While each individual's experience is distinct, both in terms of their ABI, their unique life history and personal circumstances, the participants shared a common experience of care: having received acute emergency care for ABI within the NHS context and having all attended a group rehabilitation intervention. The analysis was approached from the perspective of seeking to explore participant experiences of clinical care and rehabilitation, in relation to their overall experience of living with an ABI.

A cross-case analysis examined patterns which emerged across the individual narrative interviews (Josselson, 2011). Group themes and processes, where identified, were interpreted with reference to this collective experience of care and the role of rehabilitation in the formation of patient narratives. Both convergent and divergent themes across the group allowed an insight into both the individual narratives and the common experience of group rehabilitation following ABI.

Participants

Eleven participants were recruited from a purposive sample of ABI survivors who had all attended an outpatient neuropsychological rehabilitation group in the North East of Scotland⁶. All participants were over 18 years of age and at least one-year post ABI. Participants were excluded from consideration if they were receiving current treatment for a severe mental health disorder, receiving ongoing treatment for a significant health condition which may impact on their identity, such as cancer, and if they were not deemed to have capacity to consent to involvement in the study. The participants were not therefore representative of the ABI population as a whole, but a selective group for whom this form of rehabilitation may be appropriate. Participants were recruited from two separate cohorts of the group which ran approximately ten months apart. A summary of the participants' background information is provided (Table 1). Medical records of assessment of injury were not available; however, participant reports would indicate a heterogeneous mixture of injury types, severities and treatment experiences.

The research was approved by an NHS Research Ethics Committee (appendix F), all participants consented to be contacted and their general practitioner (GP) was informed of their participation in the research. All participants were made aware of their right to withdraw from the research at any time, and were informed of what the research process would entail, how the data would be collected, analysed and the intention to publish with the inclusion of anonymous quotations (appendix G).

⁶ The Brain Injury Rehabilitation Group (BIRG) is a Clinical Psychology led outpatient intervention delivering group Neuropsychological Rehabilitation five hours a week for 12 weeks. Attendance of the BIRG follows a suitability screening conducted by a qualified Clinical Psychologist, specialising in the field of ABI. Participants must be at least one year post-ABI and are referred via a community pathway.

Table 1: Participant characteristics

<i>Pseudonym</i>	<i>Cohort</i>	<i>Gender</i>	<i>Age</i>	<i>Self-reported Injury details</i>	<i>Self-reported initial treatment context</i>	<i>Months from injury to first Group session?</i>
Jane	2015	Female	51	Stroke	1 week acute care Post acute inpatient rehabilitation (4 months)	36
Paul	2015	Male	46	Closed head injury – Road Traffic Accident (RTA)	2 weeks Intensive care unit (ICU) Post acute inpatient rehabilitation (3 months)	24
Tim	2015	Male	42	TBI in RTA	9 days ICU, then orthopedics Discharged following acute care	24
Chris	2015	Male	51	Subarachnoid Haemorrhage	3 surgeries over three years Discharged following acute care	96
Alan	2015	Male	52	Anoxic brain injury	Unconscious for many weeks Post acute inpatient rehabilitation (18 months)	336
Jim	2015	Male	64	Intracranial Haemorrhage	No inpatient stay Discharged following acute care	12
Sarah	2015	Female	41	Stroke	Six weeks in hospital, discharge from cardiology Discharged following acute care	48
Alice	2014	Female	51	Intracranial Haemorrhage	Unreported length of acute care Discharged following acute care	144
Brian	2014	Male	55	Subarachnoid Haemorrhage	2 weeks HDU Post acute inpatient rehabilitation (4 months)	24
Harry	2014	Male	43	Closed Head injury	Unconscious for many weeks Discharged following acute care	324
Louise	2014	Female	31	Anoxic/Hypoxic Injuries	Post acute inpatient rehabilitation (3 months)	48

Procedure

Recruitment. Participants were made aware of the research by the rehabilitation group co-ordinator, were given a recruitment pack and consented to be contacted directly. Participants agreed to take part in a semi-structured interview followed by the member validation process. Basic demographic information was collected from the group co-ordinator with the consent of participants.

The semi-structured interview. The interviews were digitally recorded and lasted between 45-100 minutes. Pre-established semi-structured interviews were conducted, recorded and transcribed verbatim by the researcher. During the interviews participants were invited to speak freely about their personal experiences of living with a brain injury and the process of rehabilitation. Questions were designed to elicit narratives across the rehabilitation journey, however, the wording was kept intentionally open and participants were encouraged to tell their story, from their own perspective (Appendix H). Throughout the transcription and during an initial reading of each individual narrative the researcher's first impressions were recorded in the research diary.

Member validation. The cross case analysis of the semi-structured interviews was summarised and shared with all participants. Participants were asked for feedback on the sense and accuracy of the analysis and were asked for any changes or comments they would like to make (McCormack, 2004). By inviting the participants to engage in this process the researcher sought to enhance the validity and transparency of the narrative analysis, whilst also engaging participants in the reflexive process.

Analytic approach

The analysis was approached from an experience orientated narrative standpoint which assumes that narratives are: sequential and meaningful, definitively human, 're-present' experience and display transformation or change (Squire, 2008). Narrative analysis is situated in the hermeneutic tradition, developing hypotheses in a hermeneutic circle – a cyclical analytical movement from the whole to the parts, and back to the whole. This process distinguishes narrative analysis from other forms of analysis, as it "endeavours to explore the whole account rather than fragmenting it into discursive units or thematic categories" (Josselson, 2011, p. 229). To this end the research proceeded in three overlapping phases:

- a) A within-cases 'holistic-content' perspective was employed with attention to emergent patterns and narrative turning points (shifts in identity construction) relating to the scope of the research question (Lieblich, 1998).

- b) A recursive coding procedure using the thematic narrative analysis to identify within case narrative themes, from which core themes began to emerge across cases (Riessman, 2008).
- c) Alongside, and informing these processes, reflective strategies were used to identify discursive influences of researcher 'co-construction' and contextual factors such as the interview itself, family dynamics and the wider systemic influences (Mishler, 1986). This process served to enhance transparency in the research (Lieblich, 1998; Riessman, 2008).

Using a narrative methodology entails paying close attention to not only the content of the narrative, but also how narratives are constructed (Hiles & Čermák, 2007). Interviews are understood to be an 'active' process wherein narratives are necessarily co-constructed (Holstein & Gubrium, 2004). The interviewer was aware of their role in this process and made judgements as to how to encourage narrative generation. Interviews were allowed to find a natural end, with attention paid by the interviewer to the narrative structure of emergent stories, listening for concluding events or remarks (Labov, 1982). The context and construction of participant narratives entails an inherent subjectivity, which is both explicit and meaningful (Lieblich, 1998). Reflective notes were recorded in a research diary by the interviewer following each interview, in order to document reflections on the process of conducting the interviews and researcher 'active participation', which were incorporated into the narrative analysis.

Turning Points

Within the 'holistic-content' approach themes are not considered discrete units of analysis, but are understood to develop throughout the narrative; with consideration given to the context, content, mood and evaluation of the teller, the salience each time a theme appears and any contradictions (Lieblich, 1998). *Turning points* are points of transition in the narration of the theme, signifying a development which can be analysed through attention to the interactions and context within which the transition occurs (Clandinin and Connelly, 2000). The present study uses Ollerenshaw and Creswell's (2002) 'three-dimensional approach' to analyse the development of themes within-case narratives, where shifts in the *continuity* of themes are understood to be turning points, analysed by

consideration of concurrent personal and social *interactions* and *context* in which they occur.

Analytic procedure

The within case analysis followed the ‘holistic-content’ protocol of Narrative Orientated Inquiry (NOI; Hiles & Čermák, 2008):

1. Read material without special attention until patterns emerge.
2. Put first impressions into written form noting contradictions, unusual elements, disharmonic features etc.
3. Choose specific focus and form themes which occur in a meaningful way within whole story.
4. Mark various themes, read them separately and repeatedly.
5. Develop results in several ways e.g. crossover of themes, context, main themes, marginal themes, contradictions etc. This might include examination of ‘turning points’, barriers or shifts in perspective.

Each transcript was taken to be a discrete narrative, attention was given to the distinctive features of how each participant’s experience of their self-identity and external world view, as well as their injury and rehabilitation experiences, changed over time. Subsequently, broad themes were identified with particular attention to contradictory and unusual parts of the story. To enhance the utility of the analysis in a health context, emergent themes were analysed with consideration of multi-layered approach: exploring personal, interpersonal, positional and ideological narratives (Stephens & Breheny, 2013).

A working transcript was developed (appendix I) and notes and annotations were made alongside the text and coloured markers were used to highlight the common themes under focus: identity, treatment, impact/change, psychological factors, and common minor themes (Lieblich, 1998). Coding protocols were adapted from (Braun & Clarke, 2006) in order to provide a framework for the initial ‘within-case’ analysis, which was subsequently incorporated into the cross-case analysis (appendix J). Hypothesised shifts in identity construction within the cases were labelled as turning points.

From the working transcripts a critical incident timeline⁷ was developed for each case, by resequencing the narrative in order of hypothesised phases within which ‘movements’ were observed (Lieblich, 1998). The analysis was summarised using the three-dimensional approach to narrative re-storying (Clandinin & Connelly, 2000; Ollerenshaw & Creswell, 2002); examining the interlinked episodic stories within each narrative in terms of context, interaction and continuity over time (Appendix K). This allowed a deeper understanding of the individual’s identity construction over time, and the interaction within the narrative of critical experiences. A particular focus was paid to areas relating to potential therapeutic intervention in line with the analytical focus of the research. These themes were revisited with reference to the different levels to which the narratives pertained (Lieblich, 1998). From this process individual participant narratives were developed representing the unique story of each participant’s journey through the phases of their rehabilitation and treatment (an exemplar is provided in the results section).

The researcher then progressed to re-reading the narratives as a whole group in order to develop and test theories that gave a predictive explanation of the stories as a whole. There is a necessary tension in narrative analysis when moving from individual cases to stepping back and seeing those narratives as a whole. Narrative scholars tend to keep the story intact, theorising from the case rather than from component themes (Riessman, 2008), and yet theoretical legitimacy is enhanced by multiple cases and examination of similarities and differences across cases (Miles & Huberman, 1994). Considering this tension the core themes were amalgamated without seeing the data as ‘facts’, rather as situated interpretations, seeking to enhancing reliability of interpretation, whilst patterns may also strengthen the internal validity of the research (Josselson, 2011).

The cross case analysis examined convergences and divergences, and the role and meaning of shared themes across all narratives (Riessman, 2008). This process was seen as a continuation of the hermeneutic circle, providing an extra level of thematic analysis. Themes which were seen as ‘common’ within the narratives of the eleven participants became the focus of the narrative orientated enquiry and were synthesised, building a general interpretation grounded in the themes of each within-case analysis (Noblit & Hare, 1988).

⁷ Adapted from (Miles & Huberman, 1994)

Results

Three shared themes of rehabilitation

Each participant experienced a change in their functional abilities as a result of their brain injury. Although the specific impact of their injuries varied, the framing of the research interviews led to those impacts being expressed with reference to the participants' identity across their rehabilitation narrative. The three themes below demonstrate where participants' experiences of change shared common features with respect to their identity and sense of wellbeing. The three themes relating to the focus of rehabilitation, reclaiming efficacy after ABI and the power of social comparisons are presented in a dimensional narrative format in order to demonstrate where shifts within the theme were found to have common or divergent features. Quotations are included to enrich the analysis.

Rehabilitation focus and psychological distress

Participants described a shifting focus of care and rehabilitation throughout their narratives. This focus reflected their own immediate circumstances but was also often co-constructed with care providers. This theme demonstrates the evolution of this shifting focus and its relationship to psychological distress.

Participants' experiences of initial care were as diverse as their injuries yet, within each narrative the early treatment experience was critical in establishing their initial understanding of the injury and rehabilitation focus. For example, Sarah's stroke was secondary to a life threatening heart infection. She was transferred from the stroke unit to cardiology once the threat to her life became apparent and sees this as crucial to her subsequent experience, *"I didn't get rehabilitation because the stroke wasn't the priority, it was getting the heart sorted"*. Later she explains that her understanding of stroke was framed by this experience, *"When everybody was talking about brain injury, especially at the group, I was like brain injury, but I haven't had a brain injury"*.

For all eleven participants, a physical health focus dominated their initial rehabilitation approach. In ten of the cases mobility was identified as the central measure of their progress. Alice's narrative serves as an example of this co-constructed focus, *"I was on a*

walker thing and then I got onto sticks and then... they said if I could get up and down the stairs they would put me home. So I thought I'm getting up and down the stairs if it kills me!" Once home Alice set herself the target of walking increasingly long distances in order to establish her recovery. Six of the participants did not receive any specialist inpatient rehabilitation and, as in Alice's case, the physical focus went on to dominate their early adjustment narratives. Only three of the participants described some focus on cognitive changes in their initial treatment phase. In each of these cases the cognitive focus was associated with long term inpatient rehabilitation.

For the majority of the participants the transition to the home environment highlighted the broader impact of their injuries and this represented a significant narrative turning point across cases. The psychological consequences of the injury became more apparent, as Jane explains, *"the real rehab starts when you get home, when you are left to your own devices – and that's when up here <points to head> started going bad"*. Ten of the eleven participants gave extended accounts of their psychological distress during the home adjustment period and this was commonly associated with cognitive factors. For example, Tim reported that impaired memory function compounded the distress of attempting to make sense of the accident in which he sustained his injury, whilst Harry described visual disturbances and altered balance which left him anxious to walk in the community. These broader difficulties were often narrated as being unexpected, as Jim's reflection exemplifies: *"It was like <clicks fingers> phwah, result! Dodged a bullet there! ... And then... no no no no ... come here a minute, nobody told me this"*.

During the adjustment phase interactions with health professionals appear to present an opportunity to co-construct their understanding of injury experiences. Eight participants reported interactions with medical professionals or specialist rehabilitation services in which they sought advice for adjustment difficulties. The majority of these interactions were narrated as discrete and solution focussed, with pragmatic outcomes. However, the messages conveyed in these interactions had a strong influence on participant narratives. For Paul, a diagnosis gave him hope of improvement, *"I do believe I will get back to being myself, erm, the doctors have spoken – because I asked them what's wrong with me... her words were 'clinical depression' off the back of your injury"*. This understanding is one which he returns to throughout his narrative and which influences his approach to managing his distress through prescribed medication; Sarah recalls how her physiotherapist explained,

“you’re going to have to readjust your normal”. This message shifted her understanding of the impact of her illness and influenced approach to rehabilitation.

Group rehabilitation experiences presented an opportunity to reflect upon and re-construct broader experiences of brain injury and the psychological impacts alongside learning and sharing coping strategies. Eight participants made explicit reference to these processes, which are exemplified by Tim’s account:

“Put it this way, I’m walking towards a door with a key and every little bit of information gets me closer and I’ll walk through the door and that’s it [hmm hmm]. Being with the Horizon group (BIRG) was a big chunk of that information. There was a lot of stuff there, a lot of experiences, coping strategies, people with similar experiences”.

Consistent with the co-construction opportunities presented by other care professionals, meetings with psychologists were narrated as opportunities to question and reflect. In group rehabilitation narratives this was commonly reported as adding professional validation, structure or specific advice which allowed participants to share their personal experiences. Sarah describes how this helped her explain her difficulties to her family *“...when (Psychologist) turned around and said you know, this is, this is a graph between what you could do and what you can do now and it’s just like, well actually yeah, that rings a bell and it isn’t just me saying it...”*. At the beginning of the group Sarah did not identify as having had a ‘brain injury’. Following the experience of group rehabilitation this understanding had changed, and she reflects, *“The physical side is more dramatic, you know falling over and crashing about, but the thinking side is probably harder”*. This shift in rehabilitation focus was emphasised across participant narratives. Eight of the participant narrated how group rehabilitation had broadened their understanding of the cognitive and psychological impacts of brain injury, whilst for three participants this was not a salient feature of their group narrative.

Reclaiming efficacy in valued life domains

All eleven of the participants described significant shifts in their sense of efficacy in key areas of their life. Pre injury roles and core competencies were disrupted by the injury experience and each described attempts to reclaim efficacy throughout their rehabilitation narratives. Six participants described clear re-affirming experiences relating to domains in

which they had experienced losses, whilst there were also examples of blocked or incomplete attempts to re-establish efficacy. For example, Jane had been a care assistant prior to her injury and experienced becoming a recipient of care as a key loss, *"It was really bad. I seen it from a being a carer to actually being the person that was dealing with the stroke and I found that very hard."* Jane found receiving care highly distressing and is driven, not only to re-establish her independence, but she also relates her attempts to become a carer again, *"I need to be needed, that just bottles it... that describes it..."*. Whilst still an inpatient she would listen to the other patients *"I knew the differences that they were going through"*, she explains. Subsequently, she raised money for the charity which provided her vocational rehabilitation and also agreed to give a talk to professionals *"telling people how hard it has been coming from this side"*. Five participants, including Jane, had taken voluntary or paid roles in areas which allowed them to reclaim efficacy in areas pertinent to their pre-injury identity. For example, Brian had previously had a career in technical sales and he found a placement where he was able to help trainees working towards their exams, *"I've got to be professional and make out that I do know what I'm talking about you see"*. For participants who were still attempting to rebuild efficacy related to their pre-injury identity, the importance was clearly expressed. Louise, who had been a piano teacher, described the importance of music *"I went to Uni' to study music, and now it's like... part of my soul really."*, her injury has impeded her ability to concentrate in order to play whole pieces, however, she hopes to be able to teach again in future, *"my friends were like, will you teach her when you're better? Of course I will. I'm gonna teach the twins (her brothers children), but, it really upsets me that I'm not as good as I was. It's really upsetting."* Whilst Paul, a successful businessman, expressed *"if I can get back my (anonymised) business, at least that will allow me some ability to be who I was before."*

Key turning points in participant narratives commonly related to opportunities and barriers either with relation to their brain injuries, or the intervention of external agencies. Brian is no longer able to drive due to changes in vision, which is a source of profound regret *"I would say a brain haemorrhage is just like a living curse because I can't drive"*, whilst Alan found that activities which make him feel free, such as sailing and horse-riding, are often prohibitively expensive, or require long journeys *"...I just feel everywhere I turn I get blocked, do you know what I mean [what kind of blocked?] Well, if it's not financial it's physical"*. Services were key to facilitating many of the opportunities which the research participants described. In particular, providing voluntary placements, supporting transitions

back to work and rehabilitation strategies to aid this transition. Jim's experience was typical of those described, *"...one day I thought, instead of going asking I am going to write this down [yeah]. This is a lesson I learned at (NR Group), instead of just relying on my brain."*

Social comparisons: exclusion and inclusion

This theme is broken down into two interlinked components in order to best represent the progression through participant narratives of the relationship between social understanding, identity and wellbeing within the rehabilitation narratives. Whilst experiences of exclusion were diverse across the narratives, experiences of inclusion predominantly related to brain injury group interventions.

Misunderstanding and exclusion

All of the participants experienced interpersonal misunderstanding and exclusion as a significant determiner in their social experience post-injury. These experiences occurred in at least one of the following areas: close family, friendship groups, and wider social arena. Many of the participants experienced a narrowing of previous friendship groups following their injury. Chris explains *"All the people that used to come and see you are no longer there for you, the only ones who are there are your close friends and your family. The rest then just disappeared"*. Each participant made sense of this process differently: however, they commonly attributed it to perceptions of brain injury, stigma or misunderstanding. Paul felt that many of his friends were no longer comfortable around him, saying *"I think that because of my illness and who I had become, put a lot of people off from being a friend."* Many of the participants felt they were viewed differently in public due to their cognitive impairments, reporting that they were perceived be drunk, stupid or different; this was often attributed to the 'hidden' nature of brain injuries. Chris narrated a direct consequence of this, *"Someone from the DHS (previous name for the Department of Health) came up saying there'd been a report saying that I was falsely claiming benefit ... because they'd been looking at me and seeing no evidence whatsoever"*. Eight participants also reported how feeling misunderstood had directly impacted their relationships with partners and close family. Inconsistencies in capacity day-to-day were understood to be confusing to

family members, and this was particularly disruptive for participants who were struggling to maintain a role in the family, such as homemaker or financial provider.

Perceived stigma and misunderstanding, alongside the direct consequences of brain injury in interpersonal domains, characteristically led to a sense of exclusion or withdrawal from social arenas. Paul, for example, responded by isolating himself, *"I closed myself off from the world because I just felt I was by myself and people wouldn't understand because I don't think people can understand"*. Within participant narratives social impacts were felt to be direct result of their brain injury, which is powerfully represented by Tim, *"Where I am now, from where I was, I'm a complete and utter mess at the moment... I really don't like who I am or what I am... even in a room full of people I feel completely alone"*.

In contrast, five participants described non-critical relationships with family and friends which were seen as beneficial at times of distress. A key feature of these relationships appeared to be the non-evaluative approach taken with respect to the brain injury. This allowed a sense of 'normality' and a continuity with pre-injury identity. Jane describes a supportive close friend, *"I can be myself with her pre stroke and after... You know she meant a lot to me and it meant a lot to me as well for me to confide a lot of things, even the deepest darkest things"*. A particular feature of non-critical relationships was that participants reported being able to acknowledge and discuss their impairments more openly.

Group comparison and identification

All participants had attended a Clinical Psychology led twelve-week rehabilitation group, whilst six had also attended a community vocational rehab service which included brain injury group workshops. For all but one of the participants, peer relationships led to a shift in their narratives of identity. This was most often attributed to mutual understanding and a strong feeling of identification. Jim describes his experience of attending the NHS group in relation to prior experiences of misunderstanding:

"I felt like I was taken out of isolation, in the family, because everybody knew [yeah] everybody knew. So, as opposed to me saying to my wife, 'I can't do that' and her saying 'how can't you do it' and me 'well, how do you explain!' There I could say, I was trying too but I wasn't up to it, and people would just know".

This experience of acceptance and openness was echoed by the majority of participants. Two participants reported a more ambivalent experience, and key to both were limiting statements with respect to identification through self-comparison with other group members. Participants who were able to make positive self-appraisals in respect to their peers reported psychological benefits, for example, Paul felt relieved that he had suffered fewer physical injuries to some of his peers, and Tim identified that others had *"lost more"*. In both of the more ambivalent narratives, this process was reversed. For example, whilst Alan felt included in the group, he felt that many of the other group members were making more progress.

The benefits of identification extended beyond the facilitated groups, with participants organising group meetups and many reporting friendships which were maintained following group rehabilitation experiences. Participants also narrated shifts towards a 'shared' illness identity following group interventions. For example, when talking about strategies he'd learned from group sessions, Tim says *"It's the way that it makes it easier for myself, people with brain injuries, to do that [you've got a work-around] yeah"*.

Thematic interrelationships

The three dimensional themes were also interrelated within and across narratives. Shared understanding and in-group comparisons often presented opportunities for participants to reclaim efficacy and a broadening focus of their rehabilitation. For example, Tim explained that during a post group-rehabilitation meetup he had been commissioned by another group member to produce a cross-stitch (craftwork). In researching design alternatives, he was able to reclaim efficacy related to his pre-injury identity as creative problem solver. He reflects *"It's a little victory, sort of getting back to what I was like before. Every time I can get a process done [hmm] in a logical fashion then that's a win for me and that's another little step"*. Brian reported that he had given a talk to a 'stroke group' about his experience of haemorrhage. In response to his talk a member of the audience spoke openly about their own experience, and for Brian this reconnected him with his own valued identity, *"I was a salesman, I could stand up and it doesn't bother me, I could stand [in front of] a hundred folk and I could just speak out... I created that trigger in his mind, he wanted to be able to speak out"*.

The re-sequenced and re-scripted exemplar narrative at the end of this section serves to demonstrate how the above themes were connected within individual narratives.

Member checking

During the process of member checking each participant was sent a copy of the analysis, shared themes and exemplar narratives. Nine participants responded with comments confirming the significance of included themes. None of the respondents suggested changes to the analysis or the included extracts; however, a number of participants reiterated the salience of their own personal experiences in relation to the common themes. For example, Paul responded, "Being in class where we are all alike and able to discuss problems and solutions helped. Going by my personal reading of this paper, you have captured my whole lifestyle and priorities."

Exemplar narrative: Jane's story

Jane's story exemplifies shifts within all three of the interrelated themes and is typical of the sample. She was 48 years old and was working full time as a care assistant when she suffered her brain injury as the result of a stroke. She described herself pre-injury, "I was bubbly, energetic. Just loved to do lots of different things, and get involved in lots of different things at the nursing home". The stroke was a devastating and traumatic event which she felt changed her life forever. She was no longer able to work, and spent the next four months in a specialist stroke rehabilitation unit. Initially she was unable to walk or attend to her own personal care. The transition from being a carer to being cared for was particularly difficult to take and she cites this as central to her determination to overcome these physical limitations. Her primary focus during the inpatient stay was on increasing her mobility and independence. This determination is typified by her story of ascending the hospital stairs without the knowledge of the nursing team. She introduces the story linking the key components of determination and her relationship with being the recipient of care: "As soon as I was able to manage, it was like 'why am I letting other people do it for me? I've got to do it myself' and that was the reason that – oh I got in such a row for it...". The motivation to climb the stairs was set by the team itself, as she knew that she could return home once this goal was achieved. She described herself as "silly" in this story. Her post-

injury identity and focus of rehabilitation are here co-constructed with staff. Whilst in hospital, Jane seeks efficacy in a valued life domain by acting as an advisor and an advocate for other patients.

When Jane leaves hospital her determination to seek independence is increasingly challenged by the physical, cognitive and psychological impacts of her injury. She is alone in her home and only 'allowed out' once a week when she was aided by visiting rehabilitation professionals. She narrates an ongoing battle with the "deepest darkest things", her fears that she will not be able to cope, her experiences of fatigue and "terrible migraines". A shift is experienced when she is found alternative accommodation, which increased her independence; however, she narrates how she continues to "relapse up here in my brain".

She withdraws from many of her friendship groups as she feels excluded by people treating her differently compared to before her injury, "it just seemed to be the pity in people's face, and I just seemed to clock it straight away". She resists people offering to help, determined to maintain her independence. Her confidence in public places is also affected. When she becomes fatigued in public, she depicts herself as "lurking about" due to the change in her appearance and posture. She has the impression that "People often think that I'm drunk". This part of the narrative reflects the co-constructed nature of the stigma and discrimination she feels, and therefore exclusion. There are multiple misunderstandings too, from family members, which cause temporary ruptures and alter relationships. Her parents react negatively to her travelling unannounced to their house and her brother is shocked as she manoeuvres in the road. These events are distressing to Jane and shift how she views herself with respect to them; she also related this to an increased impulsivity – a change in personality. One core friendship provides a contrast to this, "I seem to block out the rest of the people, but with her she's known me for a long time". Key to this maintained friendship is that the terms of the relationship are not altered by the brain injury. She is able to confide in this friend, and this provides an expressive outlet, and a model of communicating her psychological distress. Her relationship with her sons is also reported as supportive, however, she does not feel that she can report the extent of her distress to them.

Jane describes a positive relationship with her GP, who advocated for her and referred her "time and time again" to outpatient services. Her perception is that this is unusual, "I was lucky because I got referred to Momentum (Vocational Rehabilitation Service) almost

straight away. But it's the people that, they don't know the help that's there, and there's not a lot of people will tell you the help that you need". She describes Momentum as a "lifeline" which came during at a period of psychological distress. She was able to start one day a week attending the vocational rehabilitation service, where she met others with brain injuries who understood the challenges, and non-judgemental tutors who would give her space to speak about her distress. During the workshops she was able to improve her understanding of brain injuries, learn new strategies, and broaden the focus of her rehabilitation, "Yeah – so it was physical and psychological – anger management, frustration, remembering, chunking, erm just doing all these classes.". She gradually overcame her fatigue and built up to attending three days a week, which improved her confidence, and through this service began volunteering in a hospital café. For Jane this was a significant shift, and continues to form part of her ongoing rehabilitation. This work provides efficacy, structure and a social dimension; it also allows her to build her confidence in relation to perceptions of her disability, "I get on I'm getting more confident [hmm] and, it's so, you just think 'I don't ken what people think'.".

Attending the 12-week NR Group proved to be another key event in Jane's narrative. She strongly identified with the other group members, "it was just brilliant and we felt so relaxed. We laughed a lot through the courses...", and described how the Psychologists worked to facilitate their experience: "We bonded together, and we weren't scared to say exactly what was on our minds – although (psychologist) and the rest of the staff were there, and they were trained and they knew what they were doing." In Jane's narrative this experience opened up a more reflective coping and a different perspective, which she describes, "I think a lot is to do with honesty and if you're honest with somebody, somebody else. It means that you've accepted it, and the acceptance part is the worst bit as well." She narrates a key bonding event with another group member who noticed her distress following a public confusion about her disabled bus pass. The other member supported her getting home and this facilitated a lasting friendship. Following the group Jane and other members have continued to meet up once a month and provide a mutual source of support and friendship.

Jane completes her narrative by narrating her shifted perspective on brain injury and her desire to help others. Following her involvement with the vocational rehabilitation service she and others formed a committee to put on a charity ball in order to raise money for the

brain injury charity. She engaged in this form of social activism by walking around shops handing out leaflets and making collections and describes her pride and increased efficacy at being able to do this. She reiterates her continued and validated identity as a carer, “I need to be needed and when other people need me, or need me to say anything, that is because of my need, and I need to be helpful to other people.” Jane consolidates her renewed identity by writing letters to all the bus drivers, thanking them for their help during her most difficult times. She also reports how she had begun baking again, utilising strategies from group rehabilitation to aid her in the kitchen; and she has taken up another voluntary role in the café where the rehabilitation group members meet.

Looking to the future Jane reports her intention to give a talk to professionals about living with a brain injury. In her narration of this forthcoming event she summarises both her shifted perspective and her determination to overcome the challenges which brain injury presents: “I think I understand more of the struggles that most people go through with the stroke side but I keep going back to the psychological side, that is the worst one [yeah] yeah and it’s just all the stupid thoughts that run in your head. Ken you’ll be lying in your bed watching TV and you just think ‘I could do that... no I can’t... yeah I can!’. I fight that battle every day.”

Summary of exemplar narrative

Although Jane highlights the ongoing process of rehabilitation she has also made numerous transitions throughout her journey so far. The focus of her rehabilitation has broadened from the initial physical challenges, to incorporate a cognitive and psychological focus. Her understanding has developed to the point where she feels able to share her perspective with others in a professional forum, to broaden the focus of care providers, and from her unique perspective – having seen it from both sides. This is interrelated with her determination to reclaim efficacy. Initially she does this through caring for others in hospital, and through regaining physical independence. She continues this approach in other valued life areas – taking up voluntary roles, being useful to the community and ultimately through raising charitable funds. Alongside she develops strategies to get back to baking, which she also enjoys. There are also social challenges. The way her wider social group respond to her disabilities and the perception of people in the community sometimes makes her feel uncomfortable. In addition, there are misunderstandings with her family in

response to her brain injury. This narrows the social supports available and is experienced as a form of exclusion. However, through understanding she finds inclusion and support. First from a close core friendship, then from others who have experienced brain injuries and through her voluntary work. The rehabilitation group also helps her establish understanding relationships in which she feels understood and included. The final narrative is one of reflective optimism, in contrast to the trauma and disorientation of her initial treatment. Jane expresses that living with a brain injury is an ongoing process of overcoming, but she also values her unique perspective. Raising money and thanking people who have helped her along the way is an indication of how far she has come.

Discussion

The three shared themes of ‘rehabilitation focus and psychological distress’, ‘reclaiming efficacy in valued life domains’, and ‘social comparisons: inclusion and exclusion’ develop understanding of the personal experience of post-acute rehabilitation and adjustment following brain injury. Both the rich diversity of experiences and the commonalities in these lived narratives add depth to current theory, complement current research evidence and can inform clinical practice.

Co-constructing the focus of rehabilitation

High prevalence rates of mood disorders during the first year of adjustment to ABI noted by other authors (De Wit et al., 2008; Gould et al., 2011; Van Reekum et al., 1996) was also evidenced in the current study, and for some participants continued for significantly longer periods. The relationship between psychological distress and adjustment to ABI has been linked to the psycho-social challenges that ABI survivors face during the transition home from hospital; in particular an inability to re-engage in desired occupations, dependence on others putting more strain on relationships, and the perceived challenges of accessing appropriate support (Turner, Ownsworth, Cornwell, & Fleming, 2009; Turner, Fleming, Ownsworth, & Cornwell, 2008, 2011). In the present study many participants talked of confusion regarding the appropriateness and availability of services and increased strain on family resources. Qualitative studies have highlighted the salience of identity ‘losses’

following ABI and the, often long term, struggle to accept the consequences of brain injury and redefine the self (Chamberlain, 2006; Fraas & Calvert, 2009; Levack et al., 2010; Nochi, 1998, 2000). The present study found that attempts at rehabilitation appeared to be linked to their understanding of the impact of their injuries. Initially, participants and health professionals were inclined to focus on coping with the physical implications of their injuries alongside mobility directed rehabilitation goals. When these initial goals were achieved, participants found that the same coping strategies could not necessarily be applied to the complex psycho-social difficulties which emerged following discharge from hospital. As a result, they reported feeling lost and distressed. The 'lost self' discourse in ABI has been challenged by Gelech and Desjardins (2011) who emphasised the significant continuity of identity and growth following ABI. Following discharge many participants sought support from community services; however, these experiences were variable in nature and were often dependent on the role and perspective the professional encountered. The present findings suggest that this continuity and growth does not happen spontaneously but may be *mediated* through interactions with health professionals, rehabilitation services and core friendships. Opportunities for reflective meaning making have been argued to support the formation of an adapted self-identity, and developing purpose, motivation and goals for the future (Thomas, Levack, & Taylor, 2014). However, given that a significant number of ABI patients report limited access to rehabilitation post discharge and only the minority are followed up in hospital (Thornhill et al., 2000), these opportunities are often not available. Where participants and families had not received specialist rehabilitation interventions, there was a clear misalignment between the broad biopsychosocial nature of their difficulties (Williams & Evans, 2003) and the narrow set of rehabilitation tools available to them. Psychological models of coping would suggest that this mismatch may increase the risk of psychological distress and emotion focussed coping during adjustment (Lazarus & Folkman, 1984).

The majority of participants reported that attending the outpatient NR group had broadened their understanding of the cognitive and psychological impacts of brain injury, and provided them with specific rehabilitation strategies to meet their psycho-social goals. Leventhal's Common Sense Model (CSM) of illness representations (Leventhal, Nerenz, & Steele, 1984) offers a way of understanding how psychological distress may result from a narrow understanding of the implications of ABI. Other researchers have found that illness beliefs and coping styles are implicated in ABI survivor outcomes. Snell, Hay-Smith,

Surgenor, & Siegert (2013) found, contrary to their expectations, that early positive attempts at coping were associated with poorer emotional outcomes at six months following mild traumatic brain injury whilst, in an ABI population, Rogan, Fortune, & Prentice (2013) identified that posttraumatic growth was associated with greater use of adaptive coping, lower levels of distress and stronger beliefs about controllability of the effect of brain injury. This model could potentially be used to identify the need for holistic forms of rehabilitation, by eliciting illness perceptions to assist clinical judgement.

Identity continuity as central to reclaiming efficacy

Changes in self-identity have been reported by ABI survivors as central to psychological distress experienced following brain injury (Levack et al., 2010; Nochi, 2000) and has increasingly become the focus of post-acute NR (Gracey et al., 2009; Ownsworth & Haslam, 2016). Participants in the present study described how their pre-injury identity guided their approach to rehabilitation, whilst losses were particularly salient in initial treatment narratives. Research emphasising the catastrophic loss and fragmentation of identity experienced by survivors (Chamberlain, 2006; Nochi, 1998) has been challenged by studies highlighting the persistence of core values (Martin, Levack, & Sinnott, 2015), the multiplicity of self-representations available (Thomas et al., 2014) and the potential clinical importance of validating and connecting with self-continuity post ABI (Fraas & Calvert, 2009; Gelech & Desjardins, 2011). The present study found that attempts to maintain core identities through increasing efficacy in previously valued roles were crucial to narratives of ABI adaptation. Survivors who were able to gain mastery in life areas or skills, particularly those which were initially thought compromised, were more likely to give positive reports of their rehabilitation. This supports the argument that therapeutic approaches should promote *self-continuity* alongside meaningful self-realignment (Gelech & Desjardins, 2011). A number of participants also reported benefitting from taking an active role in advocating for survivors of ABI (see also Fraas & Calvert, 2009; Nochi, 1998), although with less emphasis on the transformational significance of such experience *within* the rehabilitation process. When seen in relation to the whole narrative, advocacy appears to be both an opportunity to re-connect with a valued life role and also a way of reclaiming self-efficacy.

Perceived self-efficacy has been proposed by Cicerone & Azulay (2007) as a mediating factor in life satisfaction following ABI. These authors argued that interventions which

support mastery have the biggest influence on perceived self-efficacy; a position which is supported by participant narratives in this study. There was a strong link between narratives of successful or intended actions and participant's self-identity. Realistic opportunities to achieve in areas of personal value opened up new avenues for rehabilitation and self-confirmation – by shifting both how participants saw themselves and how they perceived themselves to be seen by others. Social Cognition Theory (Bandura, 2001) would suggest that perceived self-efficacy plays an important role in regulating coping behaviour.

Despite their cognitive difficulties participants in this study were driven by pre-injury values as much as by perceived losses. This was clearly demonstrated in the attainment of vocational roles, but more often that came at the end of a teleological sequence of actions in service of a valued life area, such as 'caring for others' or 'finding solutions'. Douglas' (2013) grounded theory investigation found that conceptualization of self was a dynamic and multifaceted process; with today's successes or failures being seen by survivors as tomorrow's self-appraised outcomes. This step-wise progress is evident in how participant narratives developed in the present study. The present study suggests that clinical approaches which seek to develop skills incrementally and build self-efficacy over time may provide clinical opportunities for re-establishing self-identity and improved wellbeing; building towards longer term goals such as vocational rehabilitation⁸, which may seem overwhelming or inconceivable during early adjustment to ABI.

In the present research, ABI group settings offered opportunities to explore perceived limitations and take risks, such as making jokes or offering each other advice. Cicerone and Azulay (2007) argue that therapist and peer feedback are effective means of changing self-efficacy beliefs, whilst in addition, there is evidence that group rehabilitation also provides opportunity for testing of, and experimentation with, previously valued identities. Acceptance and Commitment Therapy (ACT) (Hayes, 2003) has been suggested as a possible fit for clinical interventions in ABI, because of the focus on exploring multiple identities and re-engaging with valued life areas (Kangas & McDonald, 2011; Myles, 2004).

⁸ Vocational rehabilitation is well supported in ABI literature. For a review of models and evidence see Tyerman, (2012)

Establishing understanding as a foundation for adjustment

Participant experiences in the present study further evidence the social disruption and disconnection which survivors of ABI have consistently reported in the qualitative literature (Levack, Kayes, & Fadyl, 2010; Thomas, Levack, & Taylor, 2014). Some researchers have interpreted this disconnect as a passive one, with accounts of being abandoned (Jumisko, Lexell, & Soderberg, 2005) and misunderstandings of brain injuries leading to others staying away (Fraas & Calvert, 2009). Whilst other accounts have focussed on survivors reported a sense of invalidation, particularly where others expressed concern, grief or pity which is incongruent with that individual's self-image (Gelech & Desjardins, 2011; Nochi, 1998). In the *misunderstanding and exclusion* subtheme both of these elements are present; moreover, turning points within participant narratives indicated a complex bi-directional picture of social disengagement. Where participants felt misunderstood, negatively judged or not 'normal', they actively withdrew from relationships. Events of misunderstanding were often internalised and, as also observed by Gelech & Desjardins (2011), participants appeared to infer that changes in other people's behaviour reflected a judgment of their own self-worth and identity. It seems that experiences of 'otherness' are particularly aversive during the adjustment phase, leading to an active withdrawal from wider social networks and in some cases disconnection from close friends and family. In contrast, reports of positive relationships generally emphasised a continuity of valued pre-injury identities in which the impacts of ABI were not salient. However, ABI presentations are poorly understood by the general public (Ralph & Derbyshire, 2013; Simpson, Mohr, & Redman, 2000) and friendships free of misconceptions and misunderstandings were experienced as less common. This puts further pressure on remaining close friendships and family, which can themselves become isolated following brain injury (Oddy & Herbert, 2008). Whilst retreating into core and trusted relationships may at first appear protective, survivors appear increasingly vulnerable to ruptures in these relationships and, as a result, have limited opportunity to enhance their wider social networks. These issues are of particular significance when considering early adjustment, as social resources can act as a buffer against psychological distress (Douglas & Spellacy, 2000; Ownsworth, 2014) and continued group membership predicts greater life satisfaction following ABI (C. Haslam et al., 2008). Moreover, increasing social connectedness is a primary goal for survivors of ABI (Martin, Levack, & Sinnott, 2015). The importance of *shared understanding* experienced amongst other survivors of brain injury was consistently talked about by participants in the

present study. Those who strongly identified with the group reported clear benefits in motivation, validation and enjoyment of the process; for the minority who did not strongly identify, the narrative of otherness appeared to limit these very same factors. Mechanisms of understanding and identification appeared to have powerfully influenced participants' experiences of rehabilitation and coping behaviour during adjustment. For many participants, ABI group experiences stood in contrast to prior experiences of misunderstanding and stigma and offered a clear alternative to withdrawal by virtue of developing a new *shared* identity.

Participant reports provide a good fit with Social Identity Theory (SIT), which suggests that the processes of 'self-categorisation' and 'social comparison' are crucial to identity formation (Tajfel & Turner, 1979); and can influence wellbeing through shifting perceptions of illness (Haslam, Jetten, Postmes, & C. Haslam, 2009). From the SIT perspective, initial social withdrawal may be understood as an attempt to maintain a positive self-identity by avoiding social situations which serve to emphasise post-injury self and social discrepancy. Group ABI experiences were most beneficial for those who were able to both strongly identify and also make downward comparisons, e.g. that they were doing well in some area compared to others. These two factors did not seem to be at odds with each other; rather *downward* comparison to another was often narrated as enhancing self-compassion through a broader identification with the other. The one participant who emphasised an upwards comparison (that others were better off), reported associated self-criticism and lower identification with the group. Self-categorisation may also explain this more ambivalent experience, as fear of judgement and stigmatisation were at the heart of this participant's lack of identification. Feeling 'the same' as others in ABI group rehabilitation shifted participant self-narratives towards a stronger personal identification with the 'brain injured' label; and appeared, in reflective narratives, to have led to improvements in wellbeing and social adjustment. This implies that increasing the salience of illness awareness may be a promising route for therapeutic interventions.

Social identification as a catalyst for rehabilitation

Neuropsychological rehabilitation has traditionally focussed on the specific cognitive factors of brain injury (King & Tyerman, 2003), however there is a growing body of literature calling for an integration of the neuropsychological and social identity perspectives (Gracey &

Owensworth, 2012; Walsh, Fortune, Gallagher, & Muldoon, 2014). Our personal and social selves draw on the same neural processes (Volz, Kessler, & von Cramon, 2009), and cognitive rehabilitation is inseparable from the psycho-social context in which it occurs (Ben-Yishay, 2000). The present study adds to research on the impact group programmes have on the lives of survivors of ABI (Fraas & Calvert, 2009).

For the majority of participants, group rehabilitation presented their first opportunity to meet other survivors of brain injury. Research suggests group interventions following ABI are twice as likely to lead to improved self-concept than individually delivered interventions (Owensworth & Haslam, 2016) and holistic forms of rehabilitation are twice as likely to make significant gains in community functioning (Cicerone et al., 2008; Wilson, 2013).

Experiences of participants in this study give a detailed account of the specific interpersonal processes which contextualize holistic NR and form the fabric of the *therapeutic milieu* (Ben-Yishay, 2000). Whilst some reported specific benefits from skill development and specialist input, the overwhelming report was that these gains were facilitated by the shared understanding of other survivors. Many were able to be candid about their limitations for the first time allowing them share personal coping strategies, empathise with each other's unique challenges, and form a positive group identity which for some continued after the life of the programme. Enriching these interpersonal processes of identification, comparison and collaboration appears to be crucial to delivering effective post-acute NR, and meeting the long term needs of this population.

Conclusions

The present research explicates a continuum of rehabilitation and adjustment experiences from the narratives of individuals living with brain injury. Across the narratives there is a tangible sense of complex adjustment processes which are embedded in the psycho-social difficulties ABI survivors experience following their discharge from hospital. Once physically able to live in the community, survivors found that their adjustment had only just begun. In order to re-establish personal wellbeing within the complex milieu of community living, participants set upon a path of broadening their own comprehension of the impacts of brain injury, trying to re-establish efficacy in areas of value to them and seeking out understanding and identification. These challenges are not discrete, nor are they linear. Participant journeys through rehabilitation were as unique as their injuries, support

networks and their communities; however, a consistent search for a place in the world is at the heart of each. Group rehabilitation experiences appear to provide a catalyst for participant rehabilitation, creating a framework for shared identification within which survivors are able to honestly explore the challenges which they face, share coping strategies and build a positive in-group identity. Many of the participants reported continued friendships post group, enabling the continuation of their therapeutic milieu process beyond the limited timescales of the clinical intervention.

Future research and clinical implications

Despite the incidence of adjustment disorders following ABI (De Wit et al., 2008; Gould et al., 2011; Van Reekum et al., 1996) and continued impact on families many years following discharge (Oddy & Herbert, 2009), the majority of ABI survivors do not currently receive any further rehabilitation following discharge from hospital (Thornhill et al., 2000). The present study suggests that adjustment difficulties may be related to survivors' understanding of their injuries. Building a broader focus of rehabilitation perspectives in the early adjustment to ABI might allow shifts in rehabilitation to occur sooner within the adjustment trajectory. Those most in need of support may be identified by examining their illness understanding. Illness identity approaches should be further examined as a possible predictor of adjustment difficulties. This study also suggests that without access to specialist rehabilitation input, survivors with limited understanding of the psycho-social implications of their illness will continue to focus on those strategies which have been made salient within their initial hospital treatment experience. Psychoeducational interventions in early adjustment may provide a valuable resource to these individuals. In addition, training front line acute health professionals in the broader cognitive and psycho-social implications of ABI may enhance clinical practice, improve patient awareness and allow for proactive referral to community neuropsychological support services.

Continuity of self-identity and the reclaiming of efficacy could be enhanced by adopting psychotherapeutic models such as ACT (Hayes, 2003) which emphasise connecting with valued life areas and utilise behavioural techniques to gradually adjust to the implications of health conditions. Increased efficacy should also be supported by opportunity to access voluntary and vocational rehabilitation programmes, which participants in this study found particularly beneficial.

Future research should examine the psycho-social components of group therapies in order to maximise the clinical benefits of mechanisms of identification, social comparison and self-categorisation. This study suggests that these components were highly salient for participants who found such interventions beneficial. Should this be confirmed by empirical investigation, then comparison studies may help to quantify the respective social and cognitive elements of neuropsychological rehabilitation and guide further the design of holistic neuropsychological rehabilitation programmes.

Strengths and Limitations

Situating the research analysis within participants' narrated personal experiences lends a richness and depth to the individual accounts of ABI survivors' identity constructions over time. A particular strength of this approach is that it provided access to temporal accounts of how this identity transformed throughout participant journeys, through analysing the stories as a whole rather than as fragmented units (Josselson, 2011; Lieblich, 1998). Analytical credibility was enhanced through the inclusion of cross-case analysis, negative case analysis and member checking; whilst recruiting from two separate group cohorts provided triangulation (Elliott et al., 1999). Confirmability was promoted through the use of a reflexive diary and the inclusion of exemplar narratives, unedited transcripts and inclusion of detailed analytical summaries (Leavy, Cho, & Trent, 2014). Dependability is sought through detailed explication of the research procedures.

Transferability was limited due to the purposive sampling strategy and the narrative methodology. The sample was chosen to allow an investigation of both early adjustment and group rehabilitation experiences; however, group rehabilitation interventions are not widely available to the population as a whole. As this is a heterogeneous clinical population, participants gave varied accounts of their injuries and treatment experiences prior to attending the NR group and it can be assumed that this variance is much broader in the population as a whole; whilst limiting transferability this breadth of scope adds depth to the analysis. Narratives accounts are grounded in experience and constrained by social interaction; they are also influenced by context, therefore the health setting, the health professional status of the lead researcher and the location interviews may influence the productions of the participant narratives. In addition, narratives are by their very nature 'conversations' they are co-constructed with the researcher. For this very reason the story

produced is reflects not only the personal experience of the participant but also the perspective which is brought to the research by the researcher themselves (Josselson, 2011; Lieblich, 1998). These findings are not therefor intended to be generalizable to the ABI population as a whole, but to provide suggestive accounts of survivors' experiences of early adjustment and group rehabilitation. Within these limitations the present study gives a rich and personal insight into the transformational processes experienced by a cohort of 11 individuals. Despite the known heterogeneity of this clinical population there were striking similarities in their narratives of adjustment post ABI, which have clear implications for clinical practice and future research.

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Appendix A – Data extraction form

Data extraction form total sheet

Study name: To be included? Y / N
Study number: Characteristics complete? Y / N
Bias complete? Part 1 + Part 2

Part A Inclusion / exclusion criteria

Holistic? – includes group, psycho-social and cognitive (see Trexler 2000 / Coetzer 2008)

Adults Chronic – over one year Outpatient
Brain injury?
In English Has outcome – functional, behavioural, psychological or social?
Quantitative Peer-review Discrete intervention?

Part B Study Characteristics

Author, year, country:

Design: Observation Cohort Trial OR RCT (separate bias tool)

Sample source:

Participants:

Number: Gender: Mean age: Mean duration:

Diagnostic mix and means of ID:

Co-morbidity?

Intervention description + intensity / contact hours:

Outcome measures used and effect sizes

Appendix B – Adapted Risk of Bias Tool

General instructions: Grade each criterion as “Yes,” “No,” “Partially,” or “Can’t tell.”

Factors to consider when making an assessment are listed under each criterion. Where appropriate (particularly when assigning a “No,” “Partially,” or “Can’t tell” score), please provide a brief rationale for your decision (in parentheses) in the evidence table. Criteria marked *italics* are considered the most essential quality indicators for our purposes.

1) Unbiased selection of the cohort?

Factors that help reduce selection bias:

- Prospective study design and recruitment of subjects
- Inclusion/exclusion criteria
 - Clearly described (especially if not routine practice)
 - If assessed – qualified practitioner? Multiple?
- Recruitment strategy
 - Clearly described
 - Relatively free from bias (selection bias might be introduced, e.g., by recruitment via advertisement)

2) Selection minimizes baseline differences in prognostic factors?

Factors to consider:

- Was selection of the comparison group appropriate?

Note: This may not be an issue in the cohort studies we review. In general, the exposed and unexposed groups should be from the same source.

- In addition to selecting the cohort in an unbiased way, did study investigators do other things to ensure that exposed/unexposed groups were comparable?

3) Sample size calculated/5% difference?

Factors to consider:

- Did the authors report conducting a power analysis or describe some other basis for determining the adequacy of study group sizes for the primary outcome(s) of interest to us?
- Do the final numbers match the power calculation?

4) Adequate description of the cohort?

Consider whether the cohort is well-characterized in terms of baseline:

- Age
- Diagnosis
- Severity using an appropriate measure – GCS or PTA
- Mean time since injury

5) Adherence to intervention / exposure to treatment?

Factors to consider:

- Was the intervention clearly described / manualised, did it follow a specified model of HNR? (Details should be sufficient to permit replication in new studies.)
- Was the intervention delivered by appropriately qualified practitioners?
- Was the intervention standardised or individualised to patient (if individualised, was this done by an appropriately qualified practitioner)?

To clarify your score, please make a note of the method/measure used to ascertain exposure.

6) Validated method for ascertaining clinical outcomes?

Factors to consider:

- Were primary outcomes assessed using valid and reliable measures?
- Were these measures implemented consistently across all study participants?

7) Outcome assessment blind to exposure?

- Were the study investigators who assessed outcomes blind to the intervention or exposure status of participants (if self report was it specified that no professional was present or participated in assessment)?

8) Adequate follow-up period?

Factors to consider:

- Was the follow up appropriate to the measure? E.g. social integration may take longer to show effect than mood, was the follow up period justified using evidence?
- Follow-up period should be the same for all groups
 - In cohort studies, length of follow-up should be the same across all groups.
 - In nested case-control studies, period between the intervention/exposure and outcome should be the same for cases and controls.
 - OK if differences in follow-up time were adjusted for using statistical techniques, e.g., survival analysis.

9) Completeness of follow-up?

Factors to consider:

- Did attrition from any group exceed 30%?

(Attrition is measured in relation to the time between baseline/allocation and outcome measurement. Where different numbers of patients are followed up for

different outcomes, use the number followed up for the primary outcome for this calculation.)

- Did attrition differ between groups by more than 10% percent?

10) Analysis controls for confounding?

Factors to consider:

- Did the analysis control for any baseline differences between groups?
- Does the study identify and control for important confounding variables and effect modifiers?

(Confounding variables are risk factors that are correlated with the intervention/exposure and outcome and may therefore bias the estimation of the effect of intervention/exposure on outcome if unmeasured. Effect modifiers are not correlated with the intervention/exposure, but change the effect of the intervention/exposure on the outcome. Age, socio-economic status and length of time since injury may be examples of effect modifiers and confounding variables for the exposures and outcomes of interest in this study.)

11) Analytic methods appropriate?

Factors to consider:

- Was the kind of analysis done appropriate for the kind of outcome data?
 - Categorical – mixed model for categorical outcomes
 - Continuous – t-test, ANOVA etc.
- Was the number of variables used in the analysis appropriate for the sample size?

(The statistical techniques used must be appropriate to the data and take into account issues such as controlling for small sample size, clustering, rare outcomes, multiple comparison, and number of covariates for a given sample size. The multiple comparisons issue may be a problem particularly when performance results on numerous cognitive measures are being compared. When assessing change on cognitive measure over time, consider whether change score should be adjusted for baseline score, and consider distribution of baseline scores and change scores.)

Appendix C - Cochrane Risk of Bias tool for Randomised Controlled Studies

Domain	Description	Review authors' judgement
Sequence generation	Describe the method used to generate the allocation sequence in sufficient detail to allow an assessment of whether it should produce comparable groups.	Was the allocation sequence adequately generated?
Allocation concealment	Describe the method used to conceal the allocation sequence in sufficient detail to determine whether intervention allocations could have been foreseen in advance of, or during, enrolment.	Was allocation adequately concealed?
Blinding of participants, personnel and outcome assessors <i>Assessments should be made for each main outcome (or class of outcomes)</i>	Describe all measures used, if any, to blind study participants and personnel from knowledge of which intervention a participant received. Provide any information relating to whether the intended blinding was effective.	Was knowledge of the allocated intervention adequately prevented during the study?
Incomplete outcome data <i>Assessments should be made for each main outcome (or class of outcomes)</i>	Describe the completeness of outcome data for each main outcome, including attrition and exclusions from the analysis. State whether attrition and exclusions were reported, the numbers in each intervention group (compared with total randomized participants), reasons for attrition/exclusions where reported, and any re-inclusions in analyses performed by the review authors.	Were incomplete outcome data adequately addressed?
Selective outcome reporting	State how the possibility of selective outcome reporting was examined by the review authors, and what was found.	Are reports of the study free of suggestion of selective outcome reporting?

Other sources of bias	State any important concerns about bias not addressed in the other domains in the tool. If particular questions/entries were pre-specified in the review's protocol, responses should be provided for each question/entry.	Was the study apparently free of other problems that could put it at a high risk of bias?
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Possible approach for summary assessments outcome (across domains) within and across studies

Risk of bias	Interpretation	Within a study	Across studies
Low risk of bias	Plausible bias unlikely to seriously alter the results.	Low risk of bias for all key domains.	Most information is from studies at low risk of bias.
Unclear risk of bias	Plausible bias that raises some doubt about the results	Unclear risk of bias for one or more key domains.	Most information is from studies at low or unclear risk of bias.
High risk of bias	Plausible bias that seriously weakens confidence in the results.	High risk of bias for one or more key domains.	The proportion of information from studies at high risk of bias is sufficient to affect the interpretation of the results.

Criteria for judging risk of bias in the 'Risk of bias' assessment tool

SEQUENCE GENERATION Was the allocation sequence adequately generated? [Short form: <i>Adequate sequence generation?</i>]	
Criteria for a judgement of 'YES' (i.e. low risk of bias).	The investigators describe a random component in the sequence generation process such as: Referring to a random number table; Using a computer random number generator; Coin tossing; Shuffling cards or envelopes; Throwing dice; Drawing of lots; Minimization*. *Minimization may be implemented without a random element, and this is considered to be equivalent to being random.

Criteria for the judgement of 'NO' (i.e. high risk of bias).	<p>The investigators describe a non-random component in the sequence generation process. Usually, the description would involve some systematic, non-random approach, for example:</p> <ul style="list-style-type: none"> Sequence generated by odd or even date of birth; Sequence generated by some rule based on date (or day) of admission; Sequence generated by some rule based on hospital or clinic record number. <p>Other non-random approaches happen much less frequently than the systematic approaches mentioned above and tend to be obvious. They usually involve judgement or some method of non-random categorization of participants, for example:</p> <ul style="list-style-type: none"> Allocation by judgement of the clinician; Allocation by preference of the participant; Allocation based on the results of a laboratory test or a series of tests; Allocation by availability of the intervention.
Criteria for the judgement of 'UNCLEAR' (uncertain risk of bias).	Insufficient information about the sequence generation process to permit judgement of 'Yes' or 'No'.
ALLOCATION CONCEALMENT Was allocation adequately concealed? [Short form: <i>Allocation concealment?</i>]	
Criteria for a judgement of 'YES' (i.e. low risk of bias).	<p>Participants and investigators enrolling participants could not foresee assignment because one of the following, or an equivalent method, was used to conceal allocation:</p> <ul style="list-style-type: none"> Central allocation (including telephone, web-based, and pharmacy-controlled, randomization); Sequentially numbered drug containers of identical appearance; Sequentially numbered, opaque, sealed envelopes.
Criteria for the judgement of 'NO' (i.e. high risk of bias).	<p>Participants or investigators enrolling participants could possibly foresee assignments and thus introduce selection bias, such as allocation based on:</p> <ul style="list-style-type: none"> Using an open random allocation schedule (e.g. a list of random numbers); Assignment envelopes were used without appropriate safeguards (e.g. if envelopes were unsealed or non-opaque or not sequentially numbered); Alternation or rotation; Date of birth; Case record number; Any other explicitly unconcealed procedure.
Criteria for the judgement of 'UNCLEAR' (uncertain risk of bias).	Insufficient information to permit judgement of 'Yes' or 'No'. This is usually the case if the method of concealment is not described or not described in sufficient detail to allow a definite judgement – for example if the use of assignment envelopes is described, but it remains unclear whether envelopes were sequentially numbered, opaque and sealed.

BLINDING OF PARTICIPANTS, PERSONNEL AND OUTCOME ASSESSORS Was knowledge of the allocated interventions adequately prevented during the study? [Short form: <i>Blinding?</i>]	
Criteria for a judgement of 'YES' (i.e. low risk of bias).	Any one of the following: No blinding, but the review authors judge that the outcome and the outcome measurement are not likely to be influenced by lack of blinding; Blinding of participants and key study personnel ensured, and unlikely that the blinding could have been broken; Either participants or some key study personnel were not blinded, but outcome assessment was blinded and the non-blinding of others unlikely to introduce bias.
Criteria for the judgement of 'NO' (i.e. high risk of bias).	Any one of the following: No blinding or incomplete blinding, and the outcome or outcome measurement is likely to be influenced by lack of blinding; Blinding of key study participants and personnel attempted, but likely that the blinding could have been broken; Either participants or some key study personnel were not blinded, and the non-blinding of others likely to introduce bias.
Criteria for the judgement of 'UNCLEAR' (uncertain risk of bias).	Any one of the following: Insufficient information to permit judgement of 'Yes' or 'No'; The study did not address this outcome.
INCOMPLETE OUTCOME DATA Were incomplete outcome data adequately addressed? [Short form: <i>Incomplete outcome data addressed?</i>]	
Criteria for a judgement of 'YES' (i.e. low risk of bias).	Any one of the following: No missing outcome data; Reasons for missing outcome data unlikely to be related to true outcome (for survival data, censoring unlikely to be introducing bias); Missing outcome data balanced in numbers across intervention groups, with similar reasons for missing data across groups; For dichotomous outcome data, the proportion of missing outcomes compared with observed event risk not enough to have a clinically relevant impact on the intervention effect estimate; For continuous outcome data, plausible effect size (difference in means or standardized difference in means) among missing outcomes not enough to have a clinically relevant impact on observed effect size; Missing data have been imputed using appropriate methods.

<p>Criteria for the judgement of 'NO' (i.e. high risk of bias).</p>	<p>Any one of the following:</p> <ul style="list-style-type: none"> Reason for missing outcome data likely to be related to true outcome, with either imbalance in numbers or reasons for missing data across intervention groups; For dichotomous outcome data, the proportion of missing outcomes compared with observed event risk enough to induce clinically relevant bias in intervention effect estimate; For continuous outcome data, plausible effect size (difference in means or standardized difference in means) among missing outcomes enough to induce clinically relevant bias in observed effect size; 'As-treated' analysis done with substantial departure of the intervention received from that assigned at randomization; Potentially inappropriate application of simple imputation.
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Appendix D – Excluded studies with reasons

STUDY AUTHORS	REASON
Ashworth et al. (2015)	Chronicity of ABI no reported
Bornhofen and McDonald (2008)	Not holistic
Bouwens et al. (2009)	Not evaluating the intervention outcome
Braunling-Mcmorrow et al. (2010)	Residential
Cantor et al. (2014)	Not holistic
Chao (2012)	Not peer reviewed
Coetzer et al. (2003)	Preliminary data for included study
Constantinidou et al. (2008)	Residential
Doering et al. (2011)	No intervention
Falaefa (2009)	Not rehabilitation
Fortune et al. (2015)	Not holistic
Foy (2014)	Residential
Giles (2010)	Inpatient
Glintborg and Hansen (2016)	Not holistic
High et al. (2006)	Not chronic and individual
Klonoff et al. (2001)	Doesn't report pre and post measures
Klonoff et al. (2006)	Doesn't report pre and post measures
Mills et al. (2008)	Not holistic
Perna and Temple (2015)	Not holistic
Pierini and Hoeroid (2014)	Case study
Poppl et al. (2016)	Not available in English language
Sarajuuri et al. (2005)	Included inpatient treatment
Saux et al. (2014)	Individual therapy
Schoenberger et al. (2006)	No psycho-social outcome
Stringer (2011)	Not holistic
Svensden and Teasdale (2006)	Doesn't report pre and post measures
Tiersky et al. (2005)	Individual therapy
Wall et al. (2013)	Case study
Walsh et al. (2015)	Not evaluating the intervention outcome
Wilson et al. (2009)	Not holistic

Appendix E – Summary of effect sizes extracted from review papers

Study	Measure	Effect size	Data Source	Analysis used
Brands et al. (2013) Cohort	Goal Attainment Scaling (GAS)	Within Groups outcomes only Unable to report due to insufficient reporting	NOT AVAIL – quoted d's need to be adjusted for 'within group' analysis (no t-score)	Correlation between means needed
Caracul et al. (2012) Cohort	European Brain Injury Questionnaire (EBIQ) - Depressive mood (relative score) - Cog. Dysfunction (relative score) - Poor social and emotional self-regulation (self score) - Poor social and emotional self-regulation (relative score) Frontal Systems Behaviour Scale (FrSBe) - Apathy (self score) - Apathy (relative score) - Executive dysfunction (self score)	Within Groups outcomes only f.up: d = 1.64 f.up: d = 2.0 f.up: d = 1.33 f.up: d = 1.4 f.up: d = 1.0 f.up: d = 2.2 f.up: d = 0.82	Effect sizes quoted in main text - calculations for raw scores used. Stated in text as independent t-tests which were corrected for dependence between means (not able to confirm these calculations with data given as no access to correlation between means).	
Cicerone et al. (2004) Non-RCT	Community integration questionnaire (CIQ) - Treatment group - Control group	Within Groups outcomes Both showed sig change pre-post d = 1.20 d = 0.49 Interaction between groups	Effect sizes quoted in main text. Stated as derived using Cohen's <i>d</i> statistic, based on pooled variance from pre treatment	

		Sig program by time interaction effect ($F_{1,54} = 5.66, P = 0.21$) Treatment over 2x as effective.	CIQ scores. Stated d is 'within-subject' sig. difference 'between-subjects' (pre v post)
Cicerone et al. (2008) RCT	Community integration questionnaire (CIQ) - Overall - Social (only sig component) Perceived Quality of Life (PQOL) - Treatment group Perceived self-efficacy (SEsx) - Overall (treatment) - Cognitive (treatment) - Emotional (treatment) - Difference in groups	Sig difference between groups only. No factors found to be sig for CIQ within groups $d = 0.59$ $d = 0.46$ Within Groups outcomes $d = 0.40$ $d = 0.34$ $d = 0.35$ $d = 0.56$ $d = 0.26$	Effect sizes quoted in main text. Treatment effects calculated by using multivariate, repeated measures ANOVA – pre to post. ES for treatment interaction calculated using Hedge's g , for comparison of independent group pre-post scores that account for the variance between groups.
Coetzer and Rushe (2005) Cohort	European Brain Injury Questionnaire (EBIQ) - Overall (carer) - Overall (self)	Within Groups outcomes only $d = 0.25$ $d = 0.48$	Effect sizes quoted in main text.
Curran et al. (2015)	Mayo-Portland Adaptability Inventory (MPAI) - Ability - Adjustment - Participation	Within Groups outcomes only post d : self = 0.40, carer = 0.56 staff = 0.99 f. up d : self = -0.31, carer = 0.20 post d : self = 0.33, staff = 0.75 f. up d : self = -0.87, carer = -0.70	Effect sizes quoted in main text. Calculated using a 3x2 repeated measures ANOVA. ES were calculated using responder analysis in which only the

		post d: self = 0.64, carer = 0.53, staff = 1.10 f. up d: self = -0.56	data for those who completed questionnaires were included.	
Goodwin et al. (2016)	The Dysexecutive Questionnaire self (DEX) and informant (DEX-I) The Modified Carer Strain Index (CSI)	Within Groups outcomes only Behavioural/emotion = 0.57 / 0.56 Metacognitive = 0.71 / 0.23 (not sig.) Executive function = 0.51 / 0.73 Time/Practical = 0.48 Personal / Emotional = 0.47	Calculated using t-scores quoted in main text.	Cohen's $d = t / \sqrt{n}$
Goranson et al. (2003)	Community integration questionnaire (CIQ) Sig. difference between treatment and non-treatment condition	Between Groups outcomes only d = 0.63	Calculated using reported f-test statistics: F(1,37) = 4.193, $n_c = 21$, $n_t = 21$	Cohen's $d = \sqrt{F(n_t + n_c / n_t n_c) (n_t + n_c / n_t + n_c - 2)}$
Holleman et al. (2016)	Symptom Checklist- 90 (SCL-90) Anxiety (HADS + STAI- form Y) Depression (HADS + BDI-II) Quality of Life in Brain Injury (QOLIBRI)	Between Groups outcomes only d = 0.97 ($n^2 = 0.19$) d = 0.94 ($n^2 = 0.18$) d = 0.91 ($n^2 = 0.17$) d = 0.77 ($n^2 = 0.13$)	Quoted in text as n^2 , converted for comparison using effect size calculator, however, magnitude of effect remains the same.	
Malec (2001)	Mayo-Portland Adaptability Inventory (MPAI)	Within Groups outcomes only r = 0.73 d = 1.06 using t score	Calculated using the t statistic provided in the text, t = 8.35, and sample size n = 62 (for MPAI)	$r = \sqrt{t^2 / t^2 + df}$ Cohen's $d = t / \sqrt{n}$
Owensworth et al. (2000)	Head injury behaviour scale (HIBS) – relative Self regulation interview (SRSI) Sickness impact scale (SIP)	Within Groups outcomes only r = 0.693 d = 0.94 using t score	Calculated using the t statistic provided in the text, t = 4.3, and sample size n = 21 (for HIBS)	$r = \sqrt{t^2 / t^2 + df}$ Cohen's $d = t / \sqrt{n}$
Rasquin et al. (2010)	Goal Attainment Scaling (GAS)	Within Groups outcomes only	Not able to confirm the effect size	

	Frenchay activities index (FAI)	EF = 4.7 reported – unclear but large is d, if odds ratio d = 0.85 so still large Not enough data to extrapolate effect	statistic as the calculation is unclear from the text. Likely Cohen's d. Sig. calculated using ANOVA.	
Rath et al. (2003)	Problem Checklist (PCL) <ul style="list-style-type: none"> - Physical - Cognitive - Self-regulation Rosenberg self-esteem scale (RSES) Problem Solving Inventory (PSI) Problem Solving Questionnaire (PSQ) <ul style="list-style-type: none"> - Self regulation - Clear thinking Problem Solving Role-play test (PSRPT)	Within Groups outcomes only d = self 0.34, carer 0.52 d = carer 0.24 d = carer 0.37 (conventional group) d = 0.22 (innovative group) d = 0.69 (innovative group) d = 0.44 (innovative group) d = 0.58 (innovative group) d = 0.62 (innovative group)	Effect sizes quoted in paper, all within group, paired t-tests.	
Svendsen et al. (2004)	EBIQ – Overall effect vs control Pre to post small effects not specified	Between groups outcomes d = 0.95 Range of effects from 0.32 to 1.92 vs control	Effect sizes quoted in main test for overall and components of EBIQ in relation to control.	
Wolters et al. (2010)	Utrecht Coping List (UCL)	Within Groups outcomes only Changes in coping styles – effects Problem-solving: - 0.27 Passive: 0.21	Paired t-tests used - calculated using t scores	Cohen's $d = t/\sqrt{n}$

Appendix F – Research Ethics Committee approval

NRES Committees - North of Scotland

Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558458
Facsimile: 01224 558609
Email: nosres@nhs.net



24 September 2015

Mr Rohan Cook
Department of Neuropsychology
Ashgrove House
ABERDEEN
AB25 2ZN

Dear Mr Cook

Study title: Patient narratives of self and transformation following group rehabilitation post acquired brain injury (ABI)
REC reference: 15/NS/0094
IRAS project ID: 186582

Thank you for e-submitting the revised documents. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 15 September 2015.

Documents received

The documents received were as follows:

Document	Version	Date
GP/consultant information sheets or letters: GP letter	1	21 September 2015
IRAS Checklist XML: Checklist_23092015		23 September 2015
Letters of invitation to participant	3	21 September 2015
Participant consent form	3	21 September 2015
Participant information sheet (PIS)	3	21 September 2015

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
GP/consultant information sheets or letters: GP letter	1	21 September 2015
Interview schedules or topic guides for participants	2	25 August 2015

IRAS Checklist XML: Checklist_23092015		23 September 2015
Letters of invitation to participant	3	21 September 2015
Participant consent form	3	21 September 2015
Participant information sheet (PIS)	3	21 September 2015
REC Application Form: REC Form 26082015		26 August 2015
Research protocol or project proposal	1	24 August 2015
Summary CV for Chief Investigator (CI): Rohan Cook		25 August 2015
Summary CV for supervisor (student research): Ethel Quayle		17 August 2015

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

15/NS/0094	Please quote this number on all correspondence
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Yours sincerely



Sarah Lorick
Assistant Ethics Co-ordinator

Copy to: Mrs Jo-Anne Robertson
NHSG R&D Department



THE UNIVERSITY
of EDINBURGH



PARTICIPANT INFORMATION SHEET

Narratives of self and group rehabilitation after brain injury

Chief Investigator: Rohan Cook (Trainee Clinical Psychologist)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others, such as your GP and relatives, if you wish. As us if there is anything that is not clear of if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

1

WHAT IS THE PURPOSE OF THE STUDY?

This research study has been designed to explore your experience of rehabilitation following brain injury and the impact that this has had on you and your life. We are particularly interested in developing our understanding of the many factors which can impact on brain injury rehabilitation.

If you decide to participate in the study then you may subsequently be invited to attend an interview with the lead researcher, Rohan Cook (Trainee Clinical Psychologist). Shortly after this interview

has taken place you will be invited to read and comment upon the research analysis of your story as part of the research process.

2 WHY HAVE I BEEN INVITED?

You have been approached following your attendance of the Brain Injury Rehabilitation Group, as we are interested in exploring your experiences alongside others who have attended a similar rehabilitation programme. As part of this research it is anticipated that twelve individuals will be interviewed and will have their experiences included in the research.

3 DO I HAVE TO TAKE PART?

No. It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

4 WHAT WILL HAPPEN TO ME IF I TAKE PART?

If you decide to participate in the study please return the 'consent to contact' opt-in slip in the pre-paid envelope provided. If you prefer you can telephone the chief investigator or email using the details provided above.

If you opt-in to consent to be contacted then you will receive a call from the lead researcher at a time convenient to you. During this call you will have the opportunity to ask any questions which you may have. If you are then happy to participate then an interview date will be arranged. Prior to the interview you will be asked to sign the consent form.

During the research interview you will be asked to talk about your experiences of brain injury, of brain injury rehabilitation, and the impact these experiences have had on you and your life. The duration of the research interview will be agreed to allow you to tell your story, and it may be that a second interview appointment is appropriate for this purpose. The interview will be recorded to help us look at it in more detail later.

Following the research interview your story will be transcribed (written out) and analysed using a 'narrative' research method, which means that we will examine your story in detail and pick out significant themes. As part of this method we will ask you to view the research analysis of your story and to comment on it. We will do this within three months of your interview taking place.

5 WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

We are not aware of any disadvantages or risks of taking part. However, some people may find talking about their experiences distressing.

Your GP will be informed of your participation in the research. If you become distressed during the research interview, the interview will be terminated and your GP will be contacted. Should the research team be concerned that you are at significant risk of harm during any part of the research process, we'll take the appropriate action to ensure your safety.

6 WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

There is no direct benefit to be gained from taking part in this research. However, your participation may provide valuable information for the development of our understanding of brain injury rehabilitation and aid the development of future service provision.

7 WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

All information which is collected about you during the course of the research will be kept strictly confidential. Your personal details will be kept in a locked filing cabinet in the NHS Grampian Department of Neuropsychology. Recorded interviews will be saved on a secure NHS network accessible only to the lead researcher. The interviews will be anonymised during transcription and prior to analysis. A coded identifier will be used to assist in the participant's checking of the analysis, however this list of codes will be stored securely as above.

8 WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

The findings will be written up by the lead researcher, Rohan Cook, as a thesis submitted as part of the Doctorate of Clinical Psychology at the University of Edinburgh. The findings will also be presented to the Department of Neuropsychology as part of service development, and may also be presented at a professional conference or submitted for publication in a scientific journal.

Following the completion of the research project you will be able to receive a copy of the final report and / or a summary of the research findings should you wish to receive this.

9 WHO IS ORGANISING AND FUNDING THE RESEARCH?

The study is being organised by Rohan Cook, Trainee Clinical Psychologist, working in conjunction with the University of Edinburgh and NHS Grampian's Department of Neuropsychology. This study is being undertaken as part of an educational qualification. No additional funding has been sought for this research and the researcher is not receiving payment from any other source.

1 WHO HAS REVIEWED THE STUDY?

This study has been reviewed by the University of Edinburgh Clinical Psychology Programme Ethics Committee. All research in the NHS is looked at by an independent

group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from North of Scotland REC. NHS management approval has also been obtained.

1 CONTACT FOR FURTHER INFORMATION

If you wish to take part in the study or to find out more information then please complete the opt-in slip provided and return it in the pre-paid envelope provided.

If you wish to contact the lead researcher, Rohan Cook (Trainee Clinical Psychologist) or clinical thesis supervisor, Dr Emma Hepburn (Clinical Psychologist), then you can do so using the following details:

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This research is being conducted as part of a doctoral programme at the University of Edinburgh and is supervised by Dr Ethel Quayle (Senior Lecturer in Clinical Psychology). She can be contacted by telephone on 0131 650 4272.

If you would like to contact someone independent of the study team please contact: Dr Maggie Whyte, Consultant Clinical Psychologist in the Department of Neuropsychology, on 01224 559352.

If you wish to make a complaint about the study please contact NHS Grampian:

NHS Grampian Feedback Service

Summerfield House

2 Eday Road

Aberdeen

AB15 6RE

Telephone 0345 337 6338

E-mail nhsgrampian.feedback@nhs.net

Thank you for taking the time to read this information sheet and for considering taking part in this research study.



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Participant ID Number:

CONSENT FORM

Title of Study: Narratives of self and group rehabilitation after brain injury

Chief Investigator: Rohan Cook (Trainee Clinical Psychologist)

Please Initial

1. I confirm that I have read and understand the information sheet <Version No: 3; Date: 21/09/15> for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Edinburgh, from regulatory authorities if appropriate or from the NHS Grampian, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I agree to my interview being audio recorded. I understand that anonymised quotations from this interview may be used for presentations and publications. ☐
5. I agree to my GP being informed of my participation in the study. ☐
6. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.

Appendix H – Interview Schedule

Introduction

Thank you for agreeing to meet me and take part in this interview about your personal experiences of living with a brain injury and the process of rehabilitation.

I am interested in hearing your story rather than an objective account of events. I want to understand what the injury has meant to you and how this may have changed over time.

I might ask you some questions as we go along but it is important that you tell me your story from your perspective with the emphasis on what you feel is relevant.

Do you have any questions before we begin?

Opening question

How would you describe yourself before your brain injury?

How did that [view of yourself] change in the first months following your injury?

What have you found useful following your injury?

What have you found unhelpful following your injury?

How would you describe yourself now compared to those first months following your injury?

How has the process of group rehabilitation been for you?

General prompts:

Could you tell me more about that?

Can you give me a specific example?

What stands out as important?

What did this mean to you?

End of interview:

How do you see yourself in the future?

Is there anything else you would like to add?

Thank you for taking part in this research project.

Appendix I – Transcript extract

Interview with P1

Starts with preamble about appointment and recording etc.

I:

Thank you for agreeing to take part in the interview about your personal experiences of living with a brain injury and the process of rehabilitation. I am interested in hearing your story, rather than an objective account of events. I want to understand what the injury has meant to you and how this may have changed over time. I might ask some questions along the way but it important you tell me your story from your perspective with the emphasis on what feels most relevant to you.

Do you have any questions before we begin? [no]

How would you describe yourself before your brain injury?

P1:

Before the brain injury I was working full time and just that one day changed things for me, just that one time [what were you doing] erm, I had actually been on holiday and it was my first day back at work. I feel really lucky at the time because ten minutes before I was in my shower, ten minutes later I would have been driving my car to work. So it just shows you that wee space of time. I didn't know what happened. I tried to watch my breakfast plate and use my hand and it didn't work. I still didn't register what was happening, I couldn't speak, erm, I just redialled my son because he was on the hotline thing. He had just left for his work, so he was back and within ten minutes the ambulance was called. I was conscious throughout the whole thing, I had to nod or shake my head because I couldn't speak. And that didn't last long thankfully, and that was it.

I:

Yeah, so you were just 1 minute just back from holiday and the next minute this huge event [yeah, just that one day and it changes your life forever]. That sounds like a huge [devastating] erm and so, could you describe how your life was before that happened, I mean just generally?

P1:

I was working at a nursing home, dealing with people with different areas of help. [so a nursing?] yeah, just like a care assistant yeah. I worked there full time, I really totally enjoyed it. Obviously I couldn't go back there once I had my injury. I was at ARI for one week and I was at Woodend for nearly 4 months, so it was a lot of rehab and fighting and. But I didn't give up, I just carried on through the whole thing, and that made me the person I am today I think.

I:

Brilliant. You said your son came that day – so you were working, you had a son.

P1:

Yes, I have two sons. The eldest one is D and the youngest one is DD and it was DD because he was still at home and he worked in the bridge of don. So at that point I was still at *address*, so I phoned him and he just came back. I was conscious, I didn't know what was happening to me but he kind off sussed it out. Just phoned for the ambulance as quick as that, very quick. Hmm.

I:

You said a little bit about, you didn't go back to work. So, once you... how did you see yourself as a person before your injury?

P1:

I was bubbly, energetic. Just loved to lots of different things, and get involved in lots of different things at the nursing home. I loved working there it was just like a second family because we saw more of the residents than the family did because we worked 12 hour shifts. So it was really good, really enjoyable, I loved it.

Appendix J – Example of initial coding

Line	Transcript	Stage	Theme	Notes on Identity
820	P1: I need to be needed, that just bottles it... that describes it. I need to be needed and when other people need me, or need me to say anything, that is because of my need, and I need to be helpful to other people. At the time I was in the stroke unit, it was like, when I was getting back on my feet a little bit we went to classes, ken, to get our bits and pieces and we did it in group classes, and, we all tried to do our best but they all knew at the same time, it was no big deal if we couldn't do it at that moment, but later on you did get. Because I was... approachable maybe, they put... when new people came into	B. Inpatient rehab	[Social identity] [Role]	Feeling part of a group, deriving value from relationships. Helping others is fulfilling a role / need? "I need to be needed" – helping others, relates to premorbid ID. Being a 'listener' / carer.
825			[Recovery]	Pacing – expectations in hospital. Content of classes?
			[Personal identity] [Role]	Self ID as listener. Form of reclaiming / continuity of pre-morbid self ID.

835	<p>post stroke and pre stroke and, people could just talk to me, and if I didn't understand what they were going through, it's like 'speak to one of those nurses and then say to them...' look I think you better – I wasn't breaking confidence. Just, I think you need to speak to them [hmm]. I was... I used to go up the corridor because I was at the bottom room, and you know the railings like these... I used to pull myself all the way up to the dining room and set the tables, I did that because I could. Yeah, there were things I couldn't do at that time, but when I could, I walked up and showered every morning. The only thing that was keeping me there was the stairs and (name) road.</p>			
840			[Efficacy – mastery]	Determination to reclaim competency.

845	<p>The way that I looked at it was like 'I have to climb stairs' if I want to get home, that is what I have to do.</p> <p>And I was at home for six months until I got to the place that I am now. The hardest battle is dealing with myself.</p> <p>I: And how do you see yourself in the future, over next year or so?</p> <p>P1: I'm still learning, work in progress I keep saying, because every day I do something differently, but it works. And trying to get to the point where I'm not blaming myself for everything – why do I do this why do I don't – I just have to take every day as it comes, and deal with everything as it comes [hmm] it's maybe nae right for other people but I might</p>			
		C. Home adjust	<p>[Co-construct of care] [Mobility]</p> <p>[Psych – challenge]</p>	<p>The significance of stairs and mobility as main barrier. Mobility as a measure of recovery. Hospital = Physical – see stairs story (515)</p> <p>Internal conflicts around mastery / competency.</p>
		F. Current phase	<p>[Ongoing recovery] [Integration]</p> <p>[Coping strategies – humour; pacing]</p>	<p>Integration of approaches and perspective. Psychological and physical / mastery interrelated.</p> <p>Pacing, humour, communication and coping strategies.</p>

850	<p>be right for me [great] and so that is how I deal with things, and humour as well [yeah, yeah]. I can yap for Scotland as well, in think that's why (psychologist) put my name down{laughing} [yeah, well that's great! No, erm] It just gives you different insights into different people and how they feel about the same thing. [yeah, and that's absolutely right, there's no right or wrong thing to say but the most important thing is to say how it is for you, and hopefully we've talked through some of the major things for you] yeah.</p>		<p>[Social identity] [Same but different]</p>	<p>Different perspectives on 'the same thing' collective sense of brain injury and shared ID - <i>same but different</i>.</p>
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Appendix K – Exemplar analysis summary

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
1	A: Initial treatment	Even occurred at home - "ten minutes later I could have been in the car";	Stroke; traumatic experience "I was conscious... didn't know what was happening to me"	Son came home to find her "he kind of sussed it out. Just phoned the ambulance as quick as that"	Bubbly and energetic and highly independent . (15-25)	Cognitive and psychological impacts Devastated (25); traumatized (20-40); Instant "One day changes your life forever" (25); fatigued (90)	Injury experience	Shift to disabled / lost capacity	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
1	B: Inpatient rehab	ARI for one week and Inpatient rehab for 4 months; using hydro pool and rehab facilities; multi bed wards;	Shifting identity from carer role to being cared for (60); 'bubbly and energetic to traumatised and fatigued (50) (40) Lost mobility "I couldn't walk and my whole left side was down" (60);	Being cared for by nurses and allied health professionals - OT, Physio. Dependent relationship but also grateful for care "lots of fighting for me" (65)	Full time work - able to work long hours and "loved it"; Care assistant; Work was "like second family" (50) Bubbly and energetic and highly independent . (15-25)	Identity from 'carer to cared for'; Lost independence "I can't clean my own backside", "I was being hoisted everywhere and I didn't like it" (495); Unable to work, fatigued (90); Determined 'fighter' "made me the person I am today" (35) (495)	Initial care construction	Unable to work again (30); Work in progress "I'm in rehab every day really, just a work in progress" (55); "I don't like asking for help because I feel like a failure" (125) Carer to cared for set up future opportunities for reflection (current phase) (490) Determined	Theme reintroduced 490

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
								<p> coping developed - risk of boom and bust </p>	
1	B: Inpatient rehab	<p> Climbing the stairs in ward independently; Staff focus on physical wellbeing, P1 focus on meeting criteria needed to get out. Co- constructed a narrative of </p>	<p> Desperate to get out of hospital; rebellious? Impulsivity, sense that physical the only thing keeping in hospital (75) </p>	<p> Dependent position - in relation to perceived hierarchy "I did something really silly" (515) </p>	<p> Focus on physical mobility "the only reason I was in hospital was because of where I stayed" [couldn't climb stairs] (75) </p>	<p> Co-construction with care "If the nurses knew what I was doing I'd get hell for it" (515) "She [nurse] says 'why did you do that?! 'Well if the stairs of the only reason I'm here why don't I just start doing it?' after that I was <i>allowed</i> </p>	<p> Initial care constructio n </p>	<p> Given the impression that the main focus of rehabilitation was physical, set up for this being the major challenge of injury - which turned out to not be her </p>	<p> Later warns against 'block things out' because "you need to deal with them eventually" (855) </p>

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
		mobility as key focus.				[so long as a nurse was with me] (530)		experience "but I always say the psychological effect is worse than the physical" (85)	
1	B: Inpatient rehab	Visit from 'citizen's advice' / re DLA; whilst in hospital ward - asked loads of practical questions like "how long until back on feet" (600)	It was really challenging (595) and confusing brain was 'thingimied' (610) Distressing	Fed into relationships with nurses who "phoned her and told her to got to hell";	Impact of injury recent - confused (initial treatment)	Highly confusing experience enhances sense of threat and disability	Initial care construction	Framed relationship with DVLA / Citizens advice / threat	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
1	B: Inpatient rehab	Others in the inpatient rehab coming to P1 for advice and her being able to direct them	Sense of efficacy 'always able to listen' and reward at being 'approachable' (825)	Sense of helping others important value (820)	Carer role in community (60); move to disabled in inpatient phase (495)	Despite injury able to give advice in hospital (835) given sense of self efficacy through helping others	Initial care construction	Allowed sense of continuity of ' role ' as carer in activism and recovery narrative.	Need to be needed reaffirmed at end "and if I can influence one person with my story" (865)
1	C: Home adjustment	Returned home, spending a lot of time alone; receiving outpatient care - visits from Physio and OT to help with stairs; not being able to do practical	Overwhelmed by practical tasks "I can't do this" (95); Steep learning curve	Not showing feelings to others "I was just trying to be bring and airy and inside I wasn't" (95)	During hospital treatment her focus was physical, walking and becoming physically independent (75)	Change in perspective of rehab when home "the real rehab starts when you get home... that's when it started going bad up there [points to head] (75); "... that started working up. It's all the negative thoughts..."	Impact of injury	Physical focus of treatment continues from care; Shift to seeing psychological challenges ahead "Steep learning curve at that	Changes the subject from uncomfortable negative story of going home, then gets lost - "I'm speaking rubbish

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
		things; Still dependent - "only allowed to leave the house once a week" (90)				Benefits of rehabilitation packages practical - stress balls, using hand more (470)		particular time, but I always say the psychological effect is worse" (80) (660 - 665) "The most lasting effect was the psychological one" (115) Later in rehab (current phase) discusses the benefits of this kind of intervention (470) but	sorry!" (100)

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
								perhaps less useful when in immediate distress?	
1	C: Home adjustment	Moved house with help from ? (105)	Physical focus			Physical situation improved wellbeing though practical environmental intervention "I got moved [to new location]... I'm on the ground floor level, and everything is great."	Environmen tal change	Perhaps this resolution of some of the immediate physical / environmen tal issues led to an increased focus on	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
						psychological/cognitive challenge remains "every now and again I kinda relapse up here in my brain (105)		other concerns?	
1	C: Home adjustment	Family relationships affected by misunderstanding and cognitive changes - visits parents without informing, steps out into	Impulsivity and emotional lability "I just get it into my head to just do something and I have just got to do it regardless	"Mum fell out with me... we had an argument and I left" (140); "My brother and I had a real falling out... he shouted at me and I	Prior to injury would have called in advance; mum and dad initially supportive "reading all the leaflets" and "kept referring	Misunderstanding (family and friends) - Family weren't aware of cognitive factors or how to relate to P1 now (know-about-ness?) "I take it very personally. As I say it's the silliest things to everybody else, but it's a thing for me... [pauses, self	Social world	Affected relationship with parents and increased sense of isolation. Loss of confidence / independence. Co-constructing self with	Again she curtails the narrative when describing uncomfortable feelings. Research intervenes by offering reassurance

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
		road with brother	of my safety or anyone else's safety" (160)	got a scare" (170)	back to stroke units"	criticism]" Family: (180) (130) Friends: (125)(235)(240); Positive core friendship (190) (215)		others. P1 trying to seek a +ve illness / self Identity which is counter to the one which she perceives from those around her. Withdrawal most people from before, increased pressure on core friend. Set up difficulty with mother (prior	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
								to death) (700)	
1	C: Home adjustment	Social relationships or people in the street and friends vs. one core person <i>who doesn't judge</i> (takes on role of	Fatigue and outward appearance leave her feeling stigmatised; frustrated by her limitations and fiercely defending	Perceived response of others in street; Friends offering now offering to help with things. Family	Much more independent and felt equal and competent. Able to do shopping etc.	Misunderstanding (wider social) - Public perception concern when fatigued " People often think that I'm drunk" (200)	Social world	More and concerned about being in town when fatigued (boom and bust). "I don't like people	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
		wider social circle)	independen ce where possible	(sons) and humour as coping factors.				feeling sorry for me"	
1	C: Home adjustment	GP making referrals to rehab	I was lucky	GP referred me time and time again - supportive care	Early treatment in hospital, and transition home. Bio- psycho- social impacts	Awareness of / access to community resources "I was lucky, GP referred me time and time again"(580)	Therapeutic care - Doctors	Access to physical, vocational and neuro rehabilitatio n	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No.	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
1	D: Group rehabilitation	Vocational rehab service in community - meeting other people in community rehab setting (not facilitated by qualified psychologist) 3 days a week, in groups; with a view to work placements	Seen as a rescue, a significant change in circumstances - "To me it was a life line" (265) Tiring, but able to build strength over time "I just started getting stronger physically as well as mentally" (285)	Identifies with the people there as similar "we all had problems up here [points head]" (265)"It was just, they seemed to understand " (280)	Following (Home adjustment) phase when psychological difficulties at height. "it came to me at the right time. Because I had nothing to do and I was sitting at home and that is when all the deepest darkest things	Describes meeting others with same difficulties who 'understand' (280) (330) and non-judgemental 'tutors' (290) 'don't push' (340); having structure as the key factors in her increased 'mental and physical' strength (320). Integration of understanding regarding physical, psychological and cognitive difficulties " (265) Social aspect is highlighted as significant and	Group rehab - MM	Increased 'mental and physical strength' associated with group service; The group opens up her seeing an Integrated context for herself. Able to express herself in 'understanding' group and to 'non-judgemental experts. Social Identification - not alone;	Unclear hear whether she is talking about the vocational rehab or the 12 Neuro-rehab group, however she doesn't make a distinction regarding the benefits either.

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
					bother you" (280)	hearing other's stories.		This led to being able to talk about psychological difficulties (345 - 375) and ultimately to taking a volunteering role (375)	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No.	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
1	D: Group rehabilitation	Neuropsychology led group rehabilitation - one day a week 10-3pm along with 2 qualified psychs and 8-10 other patients screened for suitability	Fantastic experience (395) Speaking alongside or listening in a large group over 12 weeks. Enjoyed having 1:1 time with psychologist too	Identifies as 'same problems but differently', 'gelled very quickly'. Discussing brain injury related materials in a group setting facilitated by trained psychologists	This comes 'after' vocational rehabilitation when already orientated to brain injury group context but relates to the earlier themes of (narrow) treatment focus and isolation	Strong identification "I'm the same" and quick bonding building positive group image (400-410) (545) "not on my own" (545) (675)(790)(850) alongside specialist input (675) seems to validate people's needs; NOTE KEY QUOTE (555 - 560) - facilitates expression, normalisation and wellbeing (catalyst), "Honesty and acceptance" (585) Promoted confidence through	Group rehab - NHS	The strong identification facilitated continued social meetups / friendships (395) (535) led to feeling (we felt) relaxed and laughing (545) and also a positive 'shared' group image which may have been helped by the validation from experts	Blends into 'medical' narrative - i.e. Problems with non-referral and lack of follow up (story 570). Contrasting her experience of therapy with medical constructs e.g. 12 weeks blocks and

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
						encouraging the adopting of strategies (680)		(410); also point of referral to vocational rehab and other services (415) (570); Led to application of strategies in personal life 'problem solving'	physical (420)

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
1	D: Group rehabilitati on	Activism' / raising money for brain injury charity ball - Walking around shops asking for sponsorship, handing out 'wee cards' /info related to BI charity. Writing letters to thank bus drivers for support during difficult times - (615 - 645)	Rewarding, self affirming - able to do it! Went to the ball 'huge success' (615) Confidence and mastery "I was the one that actually did the most" (635) Identity ' need to be needed ' (820) (carer, 60) and	Able to raise more money and 'talk to anyone' (in shops) plus, had a laugh organising it with others from group (635)	Had lost confidence in ability to do things at home - practical tasks etc. (95) had led to self- criticism and rumination (Home adjustment) ; Had lost confidence in social role too (125)(235)(2 40) Group (MM)	Social activism aligned participant with the 'brain injury' cause and allowed her to represent a positive outward focused image -> from the strong +ve identification of the group phase. Enhanced sense of confidence with social competence and self efficacy (635-645) "gave me a reason" Able to be helpful to others (820) strongly affirming	Group rehab - MM	Opened up opportunities / paths for more activism and helping others with ABI - plans to speak 'do a talk' about her experience (650) Feels understands other difficulties from both sides (reflective) (6 60)	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
			determinati on (35)		allowed shift to +ve ID?				
1	D: Group rehabilitati on	Difficulty on bus. Disabled card not accepted, bus driver demanded payment. Someone helped (paid) and later a group member	Lost confidence, didn't have money (795)	The lack of flexibility in system - bus driver - countered by a 'kind soul' on the bus and the later support by	Initial lost confidence and efficacy of home adjustment period returns temporarily here alongside self criticism however,	Misunderstanding of the system vs. support of brain injury group friend (800) demonstrated coping against adversity	Group rehab - NHS	The shared understating facilitated a support system and ultimately here P1 demonstrate s resilience. This also consolidates	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
		supported her going home		someone in the group who noticed how she was feeling (790-800)	group systems are in place?			lasting friendship.	
1	E: Vocational rehab	Volunteering in cafe - serving customers, being part of a team, 2 hours every week	Increased mastery and sense of purpose (375) getting more confident (380)	Serving customers and working with colleagues	During Initial treatment didn't think would work again; home adjustment was isolated and too much time to ruminate; Group Rehabilitatio n process facilitated	Able to see role in community, self efficacy and confidence (375- 380), also builds in structure (860) and wider social aspect with community 'meeting different people' (390)	Vocational rehab	Opens up possibilities of other 'volunteering' roles. Has arranged to work at another cafe (385) although still believes not able to do paid work (390) -	

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
					the vocational rehab (job)			Adjustment narrative	
1	F: Current phase	At home baking and other practical tasks	Started baking, "love baking" (435) Increase in mastery and confidence; increased awareness of cognitive difficulties and willingness		Had lost confidence in ability to do things at home - practical tasks etc. (95) had led to self- criticism and rumination (Home adjustment); Strategies learned at group	Started baking again and loved it. Specific strategies in co-ordination with awareness of cognitive difficulties (680) used to make cakes, attend appointment, keep safe, plan day (435 - 445) learned at Vocational rehab service (450) to enable	Group rehab	Successful strategies build confidence to try more things and build self worth / protective against psychological distress and recovery narrative (735) Wider 'integration'	Linked in end to sense of ongoing recovery and acceptance / integration of approaches (750-770) (845)

		The context	Interaction / Identity (The dynamic)		Continuity / Phase (The narrative shift)				
P. No .	Phase	Situation	Personal	Social	Past	Current/shifting point	TP Code	Future	Notes on narrative
			to use strategies		rehabilitatio n led to trying	independence and mastery.		of illness understandin g led to application of skills in current phase (755) to manage 'head is worst'	

Journal

Neuropsychological Rehabilitation

This journal

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